MEETING THE NEEDS OF BREAST CANCER SURVIVORS IN ALASKA: SURVIVORS' AND HEALTHCARE PROVIDERS' PERSPECTIVES

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Virginia Cress Parret, M.S.

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By

Virginia Cress Parret

RECOMMENDED:

Patrick Dulin, Ph.D.

Mark E. Johnson, Ph.D.

Inna Rivkin, Ph.D.

Christiane Brems, Ph.D., ABPP
Advisory Committee Chair

Christiane Brems, Ph.D., ABPP
UAA Program Director
Ph.D. Program in Clinical-Community Psychology

Jason L. Whipple, Ph.D., ABMP
Interim UAF Program Director
Ph.D. Program in Clinical-Community Psychology

APPROVED:

Patricia Linton, Ph.D.
Associate Dean, UAA College of Arts and Sciences

David R. Yesner, Ph.D.
Associate Dean, UAA Graduate School

Lawrence K. Duffy, Ph.D.
Dean, UAF Graduate School

Aug 4, 2011
Date

Abstract

Cancer is the leading cause of death in the state of Alaska and female breast cancer ranks second highest for incidence and mortality compared to all other cancers. Due to high incidence rates of women diagnosed with breast cancer each year and a growing number of survivors, it is important to examine the unmet needs of breast cancer survivors living in Alaska. The purpose of this study was to gather data about the needs of Alaskan breast cancer survivors across the continuum of breast cancer care. Study goals were accomplished via an explanatory mixed methods research design involving three distinct phases; namely, a quantitative, qualitative, and application phase. In the quantitative phase, the study drew upon an existing needs assessment dataset collected from breast cancer survivors living in Alaska to identify and bring awareness to the physical, psychological, and daily living challenges secondary to diagnosis and treatment for breast cancer. Augmenting secondary data analyses of this dataset, key informant interviews were used to elicit information from healthcare providers about their perception of breast cancer survivors' needs and how to meet these needs in Alaska. Results based on the survey responses from 309 breast cancer survivors and interviews with 31 healthcare providers revealed key barriers and services gaps along with ways to improve services for Alaskan breast cancer survivors. Broad recommendations based on all data included: 1) addressing service gaps and improving communication; 2) meeting psychosocial needs; 3) attending to needs specific to rural breast cancer survivors; 4) improving coordination of care; and 5) implementing established survivorship care plan(s) within Alaska's healthcare system. Many challenges and obstacles identified by interviewees are beyond individual providers' control and need to be addressed not only as independent practice issues, but as larger medical education and healthcare systems issues. Given these realities and findings, the study concludes with recommendations aimed toward providers serving the oncology community, hospital groups, and other key community stakeholders with the goal of providing comprehensive medical and support services to breast cancer survivors living in Alaska.

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Chapter 1 Introduction

Brief Overview of the Study

Breast cancer is a disease that touches many lives. A diagnosis of breast cancer not only affects individual patients, it affects their family members, partners, friends, and communities as a whole. Cancer is a costly disease that can drain a family's financial resources, interfere with daily life, and take a toll on the physical and psychological wellbeing of an individual, family, and community. Dealing with cancer, from being diagnosed to completing treatment, can take months to years. For the breast cancer survivors, after treatment is completed, survivorship issues remain that entail the need for many additional resources.

For oncologists and other primary care providers, in addition to having to tend to the acute physical treatment needs of cancer patients, they are faced with the challenge of having to address the physical, psychosocial, and others needs of breast cancer survivors, especially following treatment. Healthcare providers' awareness of the needs of breast cancer survivors is essential to evaluating and helping patients with a range of issues that arise along the breast cancer treatment continuum. Optimally, patients' healthcare providers will work collaboratively with other providers to meet the unmet needs of female breast cancer survivors.

For both breast cancer survivors and their healthcare providers, it is important to understand the needs of breast cancer survivors to assure that needed services can be provided or developed to continue to address and support the overall wellbeing of the individual, the family, and the community in the aftermath of cancer. This study sought to gain this understanding by examining the needs of female breast cancer survivors who live in Alaska. More specifically, this study analyzed responses from women to a breast cancer survivors' needs assessment and evaluated providers' perceptions of unmet needs of breast cancer survivors in Alaska and suggested solutions. The information gathered was used to make recommendations about how better to meet the needs of breast cancer survivors, their families, and communities. Recommendations were aimed toward providers serving the oncology community, hospital groups directly serving breast cancer

survivors in Alaska (e.g., Providence Alaska Medical Center, Alaska Regional Hospital, Alaska Native Medical Center, Fairbanks Memorial Hospital, and Mat-Su Regional Medical Center) and other key community stakeholders (e.g., Alaska Comprehensive Cancer Partnership, Breast Cancer Focus, Inc., American Cancer Society, and local support groups).

Quantitative and qualitative methodologies were utilized to gain a comprehensive understanding of the needs of breast cancer survivors and to identify avenues through which to meet these needs. Through the use of a mixed methods research approach, a broader and more complete range of research questions could be answered. Using a mixed methods approach provided a stronger basis from which to draw significant and valid conclusions. Findings provided significant guidance for the development of meaningful recommendations for better meeting the identified needs of female breast cancer survivors living in Alaska, their families, and their communities.

Significance of the Study

Cancer is the leading cause of death in the state of Alaska and female breast cancer ranks second highest for incidence and mortality compared to all other cancers. Statewide, an average of 319 Alaskan women were diagnosed annually with breast cancer between 1996 and 2004 and an average of 49 Alaskan women die each year from the disease (Alaska Department of Health & Social Services [DHSS], 2008). Of women diagnosed with breast cancer each year, approximately 85% will survive the disease (DHSS, 2006). After treatment, most women are faced with physical, psychosocial, and other concerns associated with living with or having survived breast cancer and often are challenged with successfully adjusting to survivorship.

Healthcare providers (including oncologists, primary care physicians, physical therapists, and social workers) have the opportunity to evaluate and assist patients with a range of issues that arise along the continuum of breast cancer care. It is important for providers to understand the unmet needs and unique challenges female breast cancer survivors face living in Alaska. Due to the unique geographic features of Alaska, survivors and providers are challenged with being able to receive and deliver needed

survivorship-related services in rural areas of Alaska. No current data have been published that explore the needs of female breast cancer survivors living in Alaska. In addition, no published studies have explored Alaskan providers' perceptions of needs and solutions related to breast cancer survivorship. The current study identified survivorship needs of Alaskan women from patients' and providers' perspectives and offers solutions in the form of recommendations for providers, stakeholders, and survivors.

Problem Statement of the Study

Although female breast cancer survivors in Alaska likely experience common as well as unique challenges related to survivorship, little is known about how women and providers perceive unmet needs and possible solutions. Understanding the needs of female breast cancer survivors in Alaska from both survivors' and providers' perspectives helps shed light on the complexity of their multifaceted needs and will pave the way for finding ways to better meet these needs. A report from the Institute of Medicine (IOM, 2007), *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*, proposed that identifying and addressing the psychosocial health needs of cancer survivors should become a new standard of care and that too much emphasis has been placed on physical symptoms during and following treatment. Recommendations were added to an earlier set of priorities by the same group (IOM, 2006) that called for comprehensive, coordinated follow-up care to cancer survivors. The primary recommendation was the creation of a Cancer Survivorship Care Plan that would serve as a road map for long-term follow-up care and would provide a concise, detailed summary of a given patient's diagnosis and treatment history. Given the extant literature, the current study sought to:

1. increase knowledge about the experiences and needs of Alaskan breast cancer survivors living in urban and rural areas,
2. increase information about services needed to better meet the needs of women with breast cancer living in Alaska,
3. explore and contextualize providers' perception of the needs of breast cancer survivors in Alaska,

4. develop an understanding from healthcare providers about how to meet the needs of breast cancer survivors in Alaska, and
5. develop recommendations for providers, hospital groups, and key community stakeholders about how to improve services to breast cancer survivors.

The goals of the study were accomplished in three distinct phases. Phase One consisted of conducting secondary data analyses with a quantitative dataset that included data on the needs of breast cancer survivors living in Alaska within five domains: treatment and services, communication with providers, physical wellbeing, psychological wellbeing, and daily living. Phase Two, grounded in the findings from the quantitative phase, was a qualitative phase that contextualized the quantitative findings through gaining healthcare providers' perspectives about the needs of breast cancer survivors in Alaska. Phases One and Two were used to begin to understand better the barriers and challenges that exist from survivors' and providers' perspectives and to begin to identify possible solutions. Phase Three of the study consisted of combining Phase One and Phase Two data to develop a set of recommendations to better meet the needs of breast cancer survivors. The information gathered directed the development of a survivorship cancer care plan with the intent of strengthening care coordination of services for survivors and providers in Alaska. Table 1 highlights the quantitative research domains that were analyzed based on data provided from breast cancer survivors living in Alaska and a list of qualitative domains and questions that were explored in interviews with providers.

Table 1

Quantitative and Qualitative Research Questions

Research Phase	Questions or Domains of Interest
Phase One: Quantitative Methods	
Areas of cancer-related services women are not receiving	1. What areas of cancer-related services are not being received by women in the areas of: a. Diagnostic and screening tests b. Common Breast Cancer Treatments c. Additional Treatments and Services d. Alternative and Complementary Treatments e. Formal Psychological Services f. Organized Support Services g. Daily Living
Identified Information Needs	2. What are the identified information needs of breast cancer survivors related to cancer services in Alaska? a. Diagnostic and screening tests b. Common breast cancer treatments c. Additional treatments and services d. Alternative and complementary treatments e. Formal psychological services f. Organized support services g. Physical wellbeing h. Psychological wellbeing i. Daily living challenges
Short-term and long-term concerns of survivors (physical, psychological, daily living challenges)	3. What are the long-term and short-term concerns of breast cancer survivors related to: a. Physical wellbeing b. Psychological wellbeing c. Daily living challenges

Table 1 continued

Phase Two: Qualitative Methods	Key Informant Interview Questions based on Quantitative data
	1. Based on the synopsis provided were you surprised by the findings? 2. Should there be additions or deletions based on your experience working with breast cancer survivors? 3. What are some of the circumstances that contribute to the identified unmet needs? 4. What barriers currently exist to meeting the needs of breast cancer survivors? 5. How do service gaps contribute to the unmet needs? 6. What role does access to services play in meeting the needs of breast cancer survivors? 7. Are there system changes that may help to better meet the needs of breast cancer survivors? 8. What role do cancer/survivorship care plans play and do you think they are used effectively? 9. What role can healthcare providers play in helping to better meet the needs of survivors in Alaska? 10. How could these ideas fit into the existing care structure currently in place?

Once completed, the study provided information about the following issues:

1. identification of the needs of breast cancer survivors living in Alaska related to treatment and services, communication with providers, physical wellbeing, psychological wellbeing, and daily living;
2. a summary of systemic and professional barriers faced by providers when attending to the needs of breast cancer survivors along the survivorship continuum;
3. recommendations for the development of a survivorship cancer care plan specific to the needs of breast cancer survivors in Alaska; and
4. recommendations outlining strategies for improving the continuity of healthcare from when primary oncology treatment ends and survivorship recovery begins.

Chapter 2 Review of the Literature

The National Cancer Institute (NCI, 2009a) defines cancer as diseases in which abnormal cells divide without control and can invade nearby tissues. To explain further, in normal tissue, rates of new cell growth and old cell death are kept in balance. Cancer occurs when this balance is disrupted and uncontrolled cell growth or loss of a cell's ability to undergo cell suicide or apoptosis results. Apoptosis is the mechanism by which old or damaged cells normally self-destruct. In the absence of apoptosis, cancer cells can divide and spread within specific areas of the body. The spread of cancer that developed from cells in one organ or tissue and moved to another area of the body is referred to as a *metastatic tumor* or a *metastasis* (NCI, 2009a).

Introduction to Breast Cancer

In breast cancer, uncontrolled abnormal cell division occurs within breast tissue. The breast consists of fatty, connective, and lymphatic tissue (American Cancer Society [ACS], 2010b). It is made up of lobules (glands for milk production) and ducts that connect lobules to the nipple. Cells within breast tissue can grow out of control and produce more cells that grow into tumors or growths; in some cases cells spread to other parts of the body outside of the breast tissue (ACS, 2010a). Most often, breast cancers originate in the ducts or lobules; however, some originate in other breast tissue (e.g., fibrous connective tissue, lymph, or blood vessels in the breast). Some breast cancers, referred to as in situ, are confined within the point of origin (i.e., most commonly the ducts or lobules) of the breast tissue. These types of breast cancer are often considered early indicators of more advanced invasive breast cancers. Invasive ductal breast cancers are the most common type of breast cancer and are considered invasive because they start in the lobules or ducts of the breast, but break through the ducts or glandular walls to invade surrounding tissue of the breast (ACS, 2010b). The seriousness of invasive breast cancers is determined by the stage of the disease, as will be discussed below. Based on the location of origin and the advancement of cells into areas beyond the origin of the cancerous growth, several types of breast cancer can be classified. An overview follows in Table 2.

Table 2

Types of Breast Cancer

Common Types of Breast Cancer			
Type of Breast Cancer	**Location of Origin**	**Spread of Cells**	**Comments**
Invasive Ductal Carcinoma (IDC)	Milk ducts	Invasion into nearby tissue; spread may increase to rest of body	Most common type of breast cancer
Invasive lobular carcinoma (ILC)	Lobules (milk-producing glands)	Invasion into nearby tissue; spread may increase to rest of body	Less common than IDC Higher chance of occurring in both breasts
Ductal Carcinoma in situ (DCIS)	Milk ducts	Noninvasive or contained in the point of origin	Most treatable type of breast cancer
Papillary carcinoma	Milk ducts	Arranged in small finger-like projections	A subtype of DCIS and is rarely invasive
Lobular Carcinoma in Situ (LCIS)	Lobules (milk-producing glands)	Noninvasive or contained	Thought to present markers for having a higher chance of developing breast cancer
Rare Types of Invasive Breast Cancer			
Type of Breast Cancer	**Location of Origin**	**Spread of Cells**	**Comments**
Inflammatory Breast Cancer	Soft tissue of the breast or ducts	Always considered invasive with spread to the lymphatic system	Least common (1-4%), but most aggressive type of breast cancer
Medullary carcinoma	Subtype of IDC	Always considered invasive	5% of breast cancer cases
Metaplastic Breast Cancer	Forms in the milk ducts then moves into other breast tissue	Contains several different types of cells not usually seen in breast tumors	Rare (less than 1%) type of invasive breast cancer
Paget's Disease	Areola/nipple	Always considered invasive	Identified through changes in skin surrounding the breast
Tubular carcinoma	Breast ducts	Tubular cancer cells may be mixed with ductal or lobular cancer cells	One (rare – 1%) of the slowest-growing breast cancers
Mucinous (Colloid) carcinoma	Breast tissue	Cells within the breast produce mucous	Slow-growing (2% of breast cancers)

Stage of Diagnosis

To date, two main staging systems for cancer are used, the American Joint Committee on Cancers (AJCC) and the SEER Summary Stage System. AJCC classifies tumors using information about tumor size (T), lymph nodes involvement (N), and presence or absence of distant metastases (M). Once tumor size, lymph node involvement, and metastases are determined, a stage of I, II, III, IV, V is given (NCI,

2010). For breast cancer, the disease stages range from 0 to IV with sub-staging marked by A and B for stage II and A through C for stage III. The stage of breast cancer at diagnosis determines if a woman is considered to have early-stage or advanced-stage breast cancer. The National Cancer Institute (2009b) defines early-stage breast cancer as "Breast cancer that has not spread beyond the breast or the axillary lymph nodes. This includes ductal carcinoma in situ (stage 0) and stage I, stage IIA, stage IIB, and stage IIIA breast cancers" (*para.* 1). Advanced breast cancer is defined as spreading beyond the breast and axillary lymph nodes. Advanced stages include stage IIIB, IIIC, and Stage IV. Following is an overview of breast cancer classification (Table 3) and staging (Table 4).

Table 3

Classification of Breast Cancer

Classification Categories	**Abbreviation**	**Guidelines**
Tumor (T)	Tis	in situ tumors (any size)
	T1	(0-2cm)
	T2	(2-5cm)
	T3	(>5cm)
	T4	Ulcerating or fixed
Nodes (N)	N0	Negative
	N1	Axillary node
	N2	Fixed axillary node Internal mammary node
	N3	In Infra-clavicle node
		Internal mammary and axillary nodes Supra-clavicle node
Metastasis	M0	None
	M1	Any

Table 4

Stages of Breast Cancer

Stage	Tumor Size (T)	Lymph Node Involvement (N)	Metastasis (M)
0	Tis: any size (carcinoma in situ)	N0: None	M0: None
I	T1: small (less than 2 cm)	N0: None	M0: None
IIA	T1: small (less than 2 cm)	N1: Yes	M0: None
	T2: medium (2cm-5cm)	N0: None	M0: None
IIB	T2: medium (2cm-5cm)	N1: Yes	M0: None
	T3: large (>5cm)	N0: None	M0: None
IIIA	T1: small (less than 2 cm)	N2: Yes	M0: None
	T2: medium (2cm-5cm)	N2: Yes	M0: None
	T3: large (>5cm)	N1: Yes	M0: None
	T3: large (>5cm)	N2: Yes	M0: None
IIIB	T4: any size but spread to chest wall or skin	N0, 1, 2, or 3: Yes or No	M0: None
IIIC	T1, T2, or T3: any size	N3: Yes	M0: None
IV	T1, T2, or T3: any size	N0, 1, 2, or 3: Yes or No	M1: Yes

The SEER Summary Stage system is used more often in reporting to cancer registries and for public health research and planning. Stage at diagnosis often determines the type of treatment regimen needed to treat the cancer aggressively (Young, Roffers, Ries, Fritz, & Hurlbut, 2001). The system is broken down into three categories: local, regional, and distant. Local-stage tumors are cancers confined to the breast. Regional-stage tumors have spread to surrounding breast tissue or nearby lymph nodes. Distant-stage cancers have spread to distant organs and are considered metastatic tumors. After the stage of breast cancer is determined, treatment options are presented by women's healthcare providers. The incidence of cancer, and specifically breast cancer, is high within the United States as will be discussed next.

Epidemiology of Breast Cancer in the United States

Cancer is estimated to affect one in three individuals in their lifetime through either their own diagnosis or that of a loved one. Cancer in general accounts for nearly one-quarter of deaths in the United States, exceeded only by heart diseases. In 2010, the American Cancer Society estimated 569,490 cancer deaths are expected, equating to more than 1,500 deaths a day. Approximately 1.5 million new cancer cases are expected to be diagnosed in 2010. Of those new cases, 207,090 invasive breast cancer cases and

an additional 54,010 in situ breast cancer cases will be diagnosed among women; 1,970 new cases are expected among men (ACS, 2010b). In 2010, 39,840 women and 390 men were expected to die from breast cancer (ACS, 2010c). It is estimated that 12% of women born this year will be diagnosed with breast cancer at some time in their lifetime, with 5.6% developing breast cancer between their 50th and 70th birthday (NCI, 2011c).

Men in general are at lower risk of developing breast cancer (ACS, 2010c). Male breast cancer makes up less than 1% of all cases of breast cancer in the United States (NCI, 2011b). Among women, breast cancer is the most common cancer aside from skin cancers diagnosed in the United States and only lung cancer accounts for more deaths. Women face a one-in-eight chance of being diagnosed with breast cancer over a lifetime (ACS, 2010e). Broad surveillance of invasive breast cancer began in 1975. Between 1980 and 2001, incidence rates increased; however, since 1990 there has been a steady decrease in death rates due to breast cancer (ACS, 2010c). From 1990 to 2006, a considerably large decrease in death rates was found in women younger than 50 years old (decrease of 3.2% per year) as compared to women 50 and older (2.0% per year). The decrease in breast cancer death rates illustrates the progress in both early detection and improved methods of treatment. The observed decline in breast cancer incidence between 2001 and 2004 is believed to have occurred as a result of a drop in the use of hormone replacement therapy (ACS, 2010c). A screening tool such as mammography can detect breast cancer at an early stage, when treatment is more effective and a cure is more likely. On average, mammographies are estimated to detect 80% to 90% of breast cancers in women without symptoms. It is of importance to note that screening mammography has been shown less effective in younger women due to higher breast density at a younger age (ACS, 2010c). Currently, the American Cancer Society *Guidelines for the Early Detection of Breast Cancer in Average-Risk, Asymptomatic Women* (ACS, 2010b, p. 16) are as follows:

Ages 40 and older:

- Annual mammogram
- Annual clinical breast examination
- Monthly breast self-examination (optional)

Ages 20-39:

- Clinical breast examination every three years
- Monthly breast self-examination (optional)

Subsequent to these guidelines, magnetic resonance imaging (MRI) has been shown to be more sensitive in detecting tumors in women at higher risk for developing breast cancer. Women at high risk for developing breast cancer include those who (ACS, 2010b, p. 16-17):

- have a known BRCA1 or BRCA2 mutation,
- have a first-degree relative with a breast cancer specific gene mutation,
- have a lifetime risk of breast cancer (20%-25% based on family history risk assessment tools),
- had radiation to the chest when they were between 10 and 30 years old, or
- have Li-Fraumeni syndrome, Cowden syndrome, or Bannayan-Riley-Ruvalcaba syndrome, or have a first degree relative with one of these syndromes.

Although some risk factors have been identified by scientists, known risk factors account for only a small percentage (average of 30%) of breast cancer cases. In addition to advances in screening, over the years advances in treatment (as described in more detail later on) have decreased the death rate of women diagnosed with breast cancer.

Survival Rates

With the advances in treatment and early detection, survival rates have improved substantially since the 1950s. According to the American Cancer Society, relative survival rates are determined as follows:

> Relative survival is calculated by dividing the percentage of observed 5-year survival for cancer patients by the 5-year survival expected for people in the

general population who are similar to the patient group with respect to age, sex, race, and calendar year of observation (ACS, 2010b, p. 29).

To date, national relative survival rates for women diagnosed with breast cancer are 90% after five-years post-diagnosis, 82% after 10 years, and 75% after 15 years. Location of the cancer (stage), size of the tumor, age and race of the woman, and financial resources (e.g., health insurance, socioeconomic status) all affect the relative projected five-year survival rate (ACS, 2010c). The five-year relative survival rate for *localized* or in situ breast cancer (stage 0; malignant tumors that remain within the breast tissue with no spread to lymph nodes) increased from 80% in 1950 to 98% today. For breast cancer that is *regionally* localized (malignant tumors that have spread to tissue outside the breast or to lymph nodes) the five-year relative survival rate is 84% and survival rate drops to 23% for *distant* breast cancer that has spread to other organs (ACS, 2010b). Five-year survival rate for unstaged breast cancer has been estimated at 52% (NCI, 2011c). Currently, approximately 60% of breast cancer cases are diagnosed at the localized stage (NCI, 2011c). Further, it is estimated that 33% of breast cancers are diagnosed *after* the cancer is regionally localized and 5% are diagnosed at the distant stage; for the remaining 2% staging information was unknown (NCI, 2011c).

Size of the initial located tumor also influences predicts survival rates. Tumors less than 2.0 cm are considered small; medium tumors measure from 2.0 cm to 5.0 cm; and tumors greater than 5.0 cm in size are considered large (ACS, 2010b; Chan, 2006). Larger tumors are associated with a decrease in survival rate. Five-year survival rates for tumors less than 2.0 cm in size are 94%; decrease to 80%, for tumors greater from 2.0cm to 5.0cm; and drop to 66% for large tumors (greater than 5.0 cm in size).

In addition to tumor location and size, other factors contribute to estimating survival rates for breast cancer survivors. ACS (2010b) highlights the influence of age, race, stage at diagnosis, income, and other contributing factors that appear to affect breast cancer survival. Age at diagnosis appears to have a small effect on survival rates, with younger women having slightly poorer outcomes: younger women (younger than 40

years old) have a 5-year survival rate of 83%, compared to 90% for women older than 40 years of age.

Nationally, survival rate differences have been identified across racial groups. African American women diagnosed with breast cancer are less likely to survive past five years (78%) when compared to white women (90%) (ACS, 2010b). Later stage of breast cancer diagnosis and poorer stage-specific survival are considered to be contributing factors that may account for these differences. Relatedly, differences have been observed regarding socioeconomic status. Lower income breast cancer survivors have a lower 5-year survival rate as compared to their higher-income counterparts at every stage of diagnosis. Other contributing factors that lower the relative 5-year survival rate include lack of insurance, presence of additional illnesses, unequal access to medical care, and disparities in treatment (ACS, 2010b). Although a number of factors can influence survival rates, more and more women diagnosed with the disease are surviving.

Cancer Survivorship

As the data above reveal, breast cancer survival rates are high and survivors live free of diseases or with various symptoms for many years. Not surprisingly, more than 10 million cancer survivors live in the United States today (Hanson & Kriescher, 2006), many of them breast cancer survivors. Cancer survivors account for three times the number of survivors who were alive 30 years ago. Although there are numerous cancer survivors, no concrete definition of the concept of cancer survivorship exists. Organizations have attempted to define survivorship, but they have not differentiated the concept by type of cancer. The two most commonly used definitions of survivorship currently in use have been offered by the National Cancer Institute and the Lance Armstrong Foundation. The National Cancer Institute defines cancer survivorship as follows:

> In cancer, survivorship covers the physical, psychosocial, and economic issues of cancer, from diagnosis until the end of life. It focuses on the health and life of a person with cancer beyond the diagnosis and treatment phases. Survivorship includes issues related to the ability to get health care and follow-up treatment,

> late effects of treatment, second cancers, and quality of life. Family members, friends, and caregivers are also part of the survivorship experience (NCI, 2011a, *para.* 1).

The Lance Armstrong Foundation (2011) defines a survivor and survivorship as:

> Anyone battling cancer. A survivor might be the person diagnosed, a spouse, a child, a parent, a friend or any caregiver. And survivorship begins at diagnosis, the moment the battle with cancer begins. A survivorship experience includes physical, emotional, and practical aspects. Cancer survivorship describes the many experiences and emotions that are part of living life as a cancer survivor (LAF, 2011, *para.* 1).

Attempts at defining the concept of cancer survivorship in the United States can be traced back to the mid-1980s. The National Coalition for Cancer Survivorship (NCCS) was founded as a cancer advocacy group in 1986 and at that time defined cancer survivorship as "the experience of living with, through, and beyond a diagnosis of cancer." (NCCS, 2010, "History," *para.* 1). The definition has been expanded to include family, friends, and caregivers (NCCS, 2010). One of the great milestones describing the concept of cancer survivorship was fully articulated by one of NCCS's founders, Fitzhugh Mullan, in a 1985 article entitled *Seasons of Survival: Reflections of a Physician with Cancer*, introducing the notion of survivorship phases.

Survivorship phases. Mullan (1985), a cancer survivor himself, identified and defined three stages of survival through which cancer patients progress. The first phase is referred to as the *acute survival phase*, in which the patient is initially diagnosed. During this phase, typically during the first year, the primary focus is to survive aggressive treatments and cope with the overwhelming emotions that occur when faced with potential death. The second phase of cancer survival is the *extended survival phase* and typically spans from the end of the first year to three years after treatment completion. The second phase begins at the end of the formal cancer treatment when the cancer is no longer present or its growth has been arrested and patients are faced with returning to the lifestyle they had before diagnosis. Often during this phase, patients

experience fear of recurrence of the disease. The third and final phase is the *permanent survival phase* during which sufficient time has elapsed (greater than three years) and the likelihood of a recurrence is minimal (Mullan, 1985). Kaplan (2008) outlines the three phases of cancer survivorship and relevant events as shown in Table 5.

Table 5

Phases of Cancer Survival

Acute Survival	Extended Survival	Permanent Survival
• Extends from diagnosis to completion of initial treatment • Dominated by cancer treatment and coping with effect of therapy • Confronts one's mortality • Constant elements of fear and anxiety • Importance of family and community; family needs are often overlooked	• Beginning to return to normal life after treatment completion • Period of "watchful waiting," regular follow-up examinations, intermittent therapy as needed, dealing with physical limitations secondary to treatment (e.g., fatigue, hair loss, altered body image, cognitive dysfunction) • Psychosocial support services important • Dominated by fear of recurrence	• Evolves from extended disease-free survival and low likelihood of disease recurrence • Adjustment to the "new normal" • Long-term physiological effects of treatment • Employment and health insurance concerns • Health promotion strategies

Following Mullan, Welch-McCraffy and colleagues (1989) further developed the concept of cancer survivorship and identified cancer survival trajectories (shown below). The trajectories identified by these researchers focused on short and long-term consequences of cancer and added awareness that long-term survivors can range from those living with persistent, but controlled disease, to those who are disease-free.

- The individual lives cancer-free for many years.
- The individual lives long cancer-free, but dies rapidly of late recurrence.
- The individual lives cancer-free (first cancer), but develops second primary cancer.
- The individual lives with intermittent period(s) of active disease.
- The individual lives with persistent disease.
- The individual lives beyond the age of expected death.

Cancer survivorship challenges. Since its inception, the concept of cancer survivorship has continued to evolve and efforts have progressed to identify key issues that arise on the cancer survivorship continuum. Early efforts to identify the importance of cancer survivorship date back to the 1970s, when two Italian cancer specialists, Veronesi and Martino (1978), published and brought to light the unrecognized problems in the continued management of cancer after active treatment. They brought awareness to cancer's long-term social consequences and stressed the pervasiveness of survivors' anxiety and feelings of isolation during later phases on the cancer continuum. Veronesi and Martino (1978) highlighted the prevalence and intensity of issues experienced by cancer survivors that were frequently underestimated by oncology professionals. They also made recommendations to reconfigure long-term care of patients and address gaps in patient care services through the following statements:

> One of the most important tasks of medicine and society is to do all that is possible to make the patient's life after treatment the most normal possible and similar to that led before the dramatic event. However, to obtain satisfactory results in this direction, a complete change of all the approaches to the problem of cancer would be necessary (Veronesi & Martino, 1978, p. 349).

Over 30 years later, due to growing numbers of cancer survivors alive today, efforts have continued to increase necessary resources to serve this unique and growing population. In 2004, the Centers for Disease Control and Prevention (CDC) and the Lance Armstrong Foundation (LAF) partnered to create *A National Action Plan for Cancer Survivorship*. This plan was developed to inform the general public, policy makers, survivors, providers, and others about the many challenges faced by the growing number of cancer survivors. In 2006, Hanson and Kriescher identified key policy issues that might help policy makers better understand the range of cancer survivorship issues. Topics identified included cancer as a chronic condition; comprehensive cancer control planning; health insurance issues; employment challenges; pain management policies; support, family and infertility issues; and end-of-life logistics (Hanson & Kriescher,

2006). Continued efforts are being made to identify and meet the needs of general cancer survivors in the United States.

Female breast cancer survivorship issues. The largest population of cancer-specific survivors within the survivorship framework is that of female breast cancer survivors. NCI estimates that more than 2.6 million women previously diagnosed with breast cancer are alive today nationwide (2011c), making women with a history of breast cancer the largest group of cancer survivors. Although these women may be disease-free, their cancer diagnosis and treatment course can have ongoing physical and psychological effects on their lives and wellbeing. A reduction in quality of life, especially in the areas of emotional, social, and sexual functioning, was found not only after initial treatment, (1-2 years), but remained an issue in long-term post-treatment survival (>5 years) (Holzner et al, 2001). Information has been gathered about all three phases of survivorship, namely, acute, extended and permanent.

Acute Survival Phase: During Active Treatment

Often women who receive a diagnosis of breast cancer experience acute shock and disbelief (Ganz, 2000). Women generally feel unprepared for the diagnosis and shortly thereafter are faced with an array of medical consultations and treatment decisions (Ganz, 2000). Numerous visits with healthcare providers are common during the treatment process, requiring trust in strangers providing treatment and reliance on loved ones (Boyle, 2006). Decisions about type of surgery, subsequent adjuvant therapy, and even deciding the location of where treatment will be delivered can be overwhelming (Ganz, 2000). Although making treatment decisions early after diagnosis can be difficult and overwhelming, women who felt as though they were involved in the decision-making process of their breast cancer treatment and follow-up care reported better health-related quality of life as survivors two, five, and 10 years post-diagnosis (Anderson, Bowen, Morea, Stein, & Baker, 2009).

Treatment decisions are diverse and have to be carefully considered within the context of associated side effects. The decisions mark much of the agony of the acute survivorship phase. During acute treatment, efforts are focused on ridding the body of

cancer through four main types of therapy used individually or in combination, depending on a woman's characteristics and type of breast cancer. These four primary treatment types include radiation, chemotherapy, surgery, and hormone therapy (Cukier, Gingerelli, Markari-Judson, & McCullough, 2005). *Local* treatments typically refer to surgery and radiation therapy because those types of treatment target the specific area of the cancer. Chemotherapy and hormone therapy are *systemic* treatments, in reference to the fact that the targeted agents travel through the entire blood stream for the purpose of affecting cancer cells that may have traveled outside the initial organ in which the cancer was diagnosed. Lastly, *adjuvant* treatments (typically chemotherapy and/or hormone therapy) are given for early-stage patients to decrease the probability that the cancer has escaped out of the region of the primary site. Adjuvant treatments are commonly given as a preventative measure in breast cancers as they work to destroy cancer cells before they become established in other organs (Cukier et al., 2005).

Surgery. Some form of surgery is typical among women diagnosed with breast cancer. Operations for local treatment include breast-conserving surgery, mastectomy, and axillary (armpit) lymph node sampling and removal as described in Table 6.

Table 6

Types of Breast Cancer Surgery

Type of Surgery	Description
Axillary lymph node dissection	Removal of lymph nodes in a specific area of fat under the armpit
Sentinel node biopsy	Injection of blue dye and a radioactive tracer into the tumor site during or prior to surgery and the first (sentinel) node that picks up the dye is removed and biopsied.
Lumpectomy	Removal of the breast lump and surrounding tissue
Mastectomy	Removal of all or part of the breast and sometimes other tissue
Partial (segmental) mastectomy	Removal of more breast tissue than a lumpectomy, taking only the part of the breast in which the cancer occurs and a margin of healthy breast tissue surrounding the tumor
Quadrantectomy	Partial mastectomy in which a quarter of the breast containing the tumor is removed
Simple or Total mastectomy	Removal of the breast and areola only
Extended radical mastectomy	Removal of the breast, skin, nipple, areola, chest muscles, and all axillary and internal mammary lymph nodes on both sides of the body
Halsted radical mastectomy	Removal of the breast, skin, nipple, areola, chest muscles, and all axillary lymph nodes on one side of the body
Modified radical mastectomy	Removal of the breast, skin, nipple, areola, and most of the axillary lymph nodes on the same side, leaving the chest muscles intact
Subcutaneous mastectomy	Removal of internal breast tissue only while the nipple and skin are left intact
Prophylactic mastectomy	A mastectomy performed before any evidence of cancer can be found with the purpose of preventing breast cancer

Side effects of surgeries can include pain, temporary swelling, tenderness, and hard scar tissue that forms around the surgical site (ACS, 2010a). Following surgical treatment, some women choose to have breast reconstruction, either at the same time or later on.

Radiation therapy. Radiation therapy (RT) represents an attempt to kill cancer cells using high-energy rays or particles. RT is usually recommended for cancers in which there is a probable ability for the radiation to destroy the cancer cells, while allowing surrounding normal cells to repair themselves from the injury caused by RT (Cukier et al., 2005). For breast cancer, RT may be used to destroy remaining cancer cells following breast-conserving surgery in the areas of the breast(s), chest wall, or underarm. Following a mastectomy, in cases when the tumor size is large (> 5.0 cm) or when cancer cells were detected in the lymph nodes, RT may be administered to destroy any lingering cancer cells. The administration of radiation therapy may result in the

short-term side effects of swelling and heaviness in the breast and sunburn-like skin changes in the treated area. Changes to breast tissue and skin are estimated to subside within six to 12 months (ACS, 2010a). One nearly universal side effect of radiation therapy is fatigue, which varies in severity from patient to patient (Cukier et al., 2005). Long-term effects of radiation therapy are less common than the short-term effects mentioned. A possible late effect of radiation to the chest area is fibrosis (stiffening or scarring) of the lungs. As a result, the lungs can no longer fully inflate and take in air (ACS, 2010a). Fibrosis can cause shortness of breath and less tolerance for physical activity. Another potential long-term effect of radiation is secondary cancers. Secondary cancers typically present as a different type of cancer from the initial cancer and usually do not occur for at least five years after radiation therapy (Love, 2010). Another possible long-term side effect that has been noted in the literature but not well understood is immunosuppression. Immunosuppression is thought to occur as the result of radiation affecting the body's ability to defend itself against infection and subsequent cancers (Cukier et al., 2005).

Chemotherapy. Another common breast cancer treatment that induces cancer cell death is chemotherapy. Chemotherapy drugs are typically administered either intravenously or orally depending on type of chemotherapy. Chemotherapy is given in cycles through which the drug(s) are absorbed into the blood and travel through the bloodstream to cancer cells in most parts of the body. Each period of treatment is followed by a recovery period, resulting in treatment lasting several months. The type of drugs administered, their amount, and length of treatment affect patients' experience of side effects from chemotherapy. The benefits of chemotherapy depend on the type and stage of breast cancer. Dr. Susan Love highlighted chemotherapy in general reduces the risk of reoccurrence of breast cancer by about a third and suggested women and their oncologists work collaboratively when deciding the realistic benefits of treating their breast cancer with chemotherapy (Love, 2010). ACS (2010a) identified the most common short-term chemotherapy side effects as follows:

- hair loss
- mouth sores
- loss of appetite
- nausea and vomiting
- increased chance of infections (due to low white blood cell counts)
- easy bruising or bleeding (due to low blood platelet counts)
- fatigue (due to low red blood cell counts and other reasons)

Hormone therapy. Hormone therapy (HR) is most often used as an adjuvant therapy to help reduce risk of cancer recurrence following surgery, although it may also be used for more advanced breast cancers. The hormone estrogen is thought to promote the growth of about two out of three breast cancers containing estrogen receptors (ER-positive cancers) or progesterone receptors (PR-positive cancers) (ACS, 2010a). The drug Tamoxifen is one of the most common types of hormone therapy for women with ER- or PR-positive cancers and is prescribed after surgery. Tamoxifen works by blocking the estrogen receptor in the breast and in the metastatic cancer cells, preventing estrogen from getting to them (Love, 2010). Use of Tamoxifen as an adjuvant therapy has been estimated to reduce the chances of having a cancer recurrence by about half among ER-positive and PR-positive breast cancers and a 33% reduction in the breast cancer death rate (ACS, 2010a). However, Love (2010) explained when used for too many years, the breast cells can become resistant to Tamoxifen; sometimes even starting to feed the tumor. It is recommended at this time that women not take Tamoxifen for more than five years (Love, 2010). Tamoxifen is also used to treat metastatic breast cancer, and in some cases is used prophylactically to reduce risk of developing breast cancer in women at high risk. The most common side effects of hormone therapy include fatigue, hot flashes, vaginal discharge, and mood swings; however, more serious side effects have also been reported including blood clots, strokes, uterine cancer, and cataracts (Love, 2010).

All forms of cancer treatment (including surgery, chemotherapy, hormone therapy, and radiation therapy) can have unwanted, long-term effects on tissues and organ

systems that may impair a person's health and quality of life in large and small ways (Cukier et al., 2005). For some women diagnosed with breast cancer, treatment can have a major impact on their ability to continue a normal routine with work and family. The period during treatment is the time when fear and anxiety can continue due to the uncertainty of treatment outcome. Making it through treatment successfully is an accomplishment in itself; however, once treatment is complete patients are faced with the new challenge of transitioning from being a patient to being a cancer survivor.

Transitional Period: From Patient to Survivor

The survivorship experience is described as dynamic, changing over time, with particular moments of stress being transitions, such as the transition from acute treatment to long-term follow-up care (IOM, 2006). The transition phase from completing treatment to being one year post-treatment is not part of Mullen's (1985) documented seasons of survival; however, it is an important phase researchers have begun to acknowledge as a unique phase within the breast cancer survivorship continuum. Recent emphasis has been placed on paying attention to the importance of issues that occur during the transitional phase of being a cancer patient to becoming a cancer survivor. In fact, women who had radiation or chemotherapy for primary breast or gynecological cancers were found to experience primary stressors at the end of treatment. These stressors included feelings of uncertainty about treatment, follow-up, and symptoms related to physical concerns, difficulty concentrating, attitudes about their body, and dealing with mortality (Lauver, Connolly-Nelson, & Vang, 2007). The President's Cancer Panel (2004) identified similar findings, suggesting the transitional phase can bring about mixed feelings of celebration and relief that primary treatment is finished, yet can also be accompanied by anxiety and fears about disease recurrence or treatment-related changes. Interestingly, a longitudinal study assessed measures of depression, cancer-related anxiety, cancer concerns, and quality of life at three time points: during treatment, three weeks following the end of treatment, and three months post-treatment found that, in general, breast cancer survivors were remarkably well adjusted during the months following treatment (Costanzo et al., 2007). However, the authors did find

younger age to be a predictor of greater distress. This finding is consistent with Dow and Lafferty's (2000) research that assessed younger women's (<=45 years old) quality of life, psychosocial adjustment, and survivorship issues at the start, midpoint, end, and six months following breast-conserving surgery and radiation therapy for breast cancer. Another study explored breast cancer-related symptoms post-treatment (0.5 to 14.9 months) to identify the relationship between symptoms and quality of life. Janz and her colleagues (2007) found over half of the women experienced symptoms related to fatigue, hot flashes, sleep disturbance, general pain, and breast discomfort. In addition, younger women were found to experience worse symptoms when compared to their older counterparts (Janz et al., 2007). It is apparent based on these studies that women continue to experience multiple symptoms during the vulnerable transition period to survivorship.

After primary treatment for cancer ends, cancer survivors are often faced with transitioning from being under the care of an oncology specialist to working with their primary care provider. The transition from active treatment to post-treatment care is a period of time that is critical to long-term health. If follow-up care is not provided, cancer survivors are left without knowledge of their heightened risk and a surveillance care plan of action. During the transitional phase, the goal is to optimize both continuity and coordination of care. Cancer survivors in general often require treatment from multiple providers, including surgeons, medical oncologists, radiation oncologists, nutritionists, and psychosocial or behavioral healthcare providers, who typically practice in separate sites. Due to the multitude of providers involved during and following treatment completion, survivors often face fragmented, uncoordinated care that can lead to both underuse and overuse of services (Earle, 2007). The transitional period can be greatly improved with a plan for continuing survivorship care to address women's needs during this vulnerable time.

Survivorship Care Plan

To address some of leading concerns that arise during this phase of survivorship, recommendations were published by an IOM (2006) report that focused on cancer

patients who are transitioning to becoming cancer survivors. The report was a call to action to provide comprehensive, coordinated follow-up care to cancer survivors. In addition to highlighting the physical, psychosocial, vocational, and insurance needs of adult cancer survivors, one of the report's primary recommendations was that patients completing primary treatment for cancer be given a summary of their treatment and a comprehensive plan for follow-up. A survivorship care plan is intended to inform patients and their providers of the long-term effects of cancer and its treatment, identify psychosocial support resources in their communities, and provide guidance on follow-up care, prevention, and health maintenance (IOM, 2007).

The uses of survivorship care plans are beginning to be explored, though they are still in their infancy for widespread utilization and tested effectiveness. Recently, efforts have been begun to standardize and pilot survivorship care plans in medical settings. As a response to the 2006 IOM report, the Institute of Medicine provided a 2007 publication that specifically identified the needs, challenges, and structural outline of implementing cancer survivorship care plans. IOM (2007, p. 8) identified the key elements that should be included in Survivorship Care Plans as follows:

- specific tissue diagnosis and stage
- initial treatment plan and dates of treatment
- toxicities during treatment
- expected short- and long-term effects of therapy
- late toxicity monitoring needed
- surveillance for recurrence or second cancer
- who will take responsibility for survivorship care
- psychosocial and vocational needs
- recommended preventive behaviors/interventions

Following these guidelines, Miller (2008) piloted a survivorship care plan in an outpatient clinical setting in a community hospital for breast cancer survivors. Survivors' reactions to the care plan were collected through qualitative interviews before and after the care plan was shared with each survivor. Survivors described feeling overwhelmed

after completing their therapy and did not know what questions to ask their oncologist about continuing care. After the care plan was implemented, survivors evaluated the care plan and their experience of meeting with a healthcare professional to review the care plan. All five women interviewed found the summary of their treatment to be helpful and their written plan informed them of community resources, educational support groups, and timing of follow-up appointment schedules. Overall, the plan was viewed as providing practical guidance for survivors by organizing the post-treatment care with their oncologist and primary care providers (Miller, 2008). In addition, Ganz and Hahn (2008) published specific guidelines for how oncologists can implement a cancer treatment summary and survivorship care plan for breast cancer survivors. They highlighted key components of coordination of care that would foster delivery of higher-quality cancer care. Although efforts are beginning to be made to provide better follow-up after treatment completion, breast cancer survivors continue to experience an array of physical and emotional symptoms years following the end of their treatment.

Extended Survival and Permanent Survival Phases: Years Following Treatment

As the nation's growing population of breast cancer survivors age, more efforts are being put forth to attend to their care along the survivorship continuum. Whether treatment involves six weeks of radiation therapy or four to six months of adjuvant chemotherapy, the end of treatment for breast cancer can often lead to feeling mixed emotions. Women may feel ill prepared to navigate through the recovery process of treatment. Even after having navigated through the maze of detection, treatment, and management, some individuals with cancer continue to experience an array of problems. Following the first year post-treatment, cancer survivors are considered to be in the extended survival phase until they are more than three years post-treatment when they are considered to be in the permanent survival phase. Researchers have placed importance on survivors' quality of life and symptom expression among breast cancer survivors in the extended survival phase (Ahles et al., 2005; Ganz, 2000; Ganz et al., 2002; and Holzner et al., 2001). Less work has focused on permanent survivors, though most research as mentioned above does not differentiate these two phases.

During the extended and permanent phases of survival, breast cancer survivors have been found to experience an array of physical and emotional concerns. Extended or permanent cancer survivors have special concerns, such as increased risk or fear that cancer will recur, late-appearing side effects from treatment, changes in family roles and daily activities, rehabilitative care, and financial impact of cancer treatment and short- or long-term disability (Feuerstein, 2007). Other challenges faced by cancer survivors on an ongoing basis can include the presence of recovery issues such as fatigue, cognitive changes, body image changes, sexual health and functioning, infertility, post-traumatic stress disorder (PTSD), and stress symptoms. Additional issues related to family or caregiver distress and socioeconomic issues have also been found to be present during survivorship years following cancer treatment completion (Alfano & Rowland, 2006; Boyle, 2006). Several lingering physical and emotional concerns are particularly noteworthy.

Ongoing physical concerns. Following treatment completion, women may continue to experience a variety of physical symptoms that include fatigue, difficulty sleeping, pain, hot flashes, sexual dysfunction, weight gain, difficulty remembering things, and poor concentration (Cappiello, Cunningham, Knof, & Erdos, 2007; IOM, 2004). Janz and colleagues (2007) further identified that survivors may experience breast symptoms related to pain, oversensitivity, skin problems, and swelling in the breast. Three of the most common physical concerns reported by breast cancer survivors include cancer-related fatigue, sexual dysfunctions, and memory and cognition difficulties.

Cancer-related fatigue. The term cancer-related fatigue (CRF) has been recognized and defined by the National Comprehensive Cancer Network (NCCN) as "a distressing persistent, subjective sense of physical, emotional and/or cognitive tiredness or exhaustion related to cancer or cancer treatment that is not proportional to recent activity and interferes with usual functioning" (NCCN Guidelines, 2010a, p. FT-1). This type of fatigue is recognized as a common and, at times, debilitating complaint among cancer survivors (Bower et al., 2006; Cappiello et al., 2007; Ganz & Bower, 2007; Janz et al., 2007). Until recently, the medical community has under-appreciated this common

symptom experienced by cancer survivors (Ng, Alt, & Gore, 2007). A longitudinal study was conducted by Bower and colleagues that explored the symptoms of fatigue at one to five years and at five to 10 years after receiving a diagnosis of breast cancer.

Findings showed a lack of change in fatigue symptom over time. Interestingly, women who reported higher levels of depressive symptoms and who had high blood pressure at baseline were more likely to be fatigued at follow-up. In addition, women treated with radiation and chemotherapy were more likely to be fatigued than women treated with radiation alone (Bower et al., 2006). Examining breast cancer and Hodgkin's disease survivors, Ganz and Bower (2007) confirmed CRF persists long after cancer treatment ends and is most commonly associated with more intensive types of cancer treatment (e.g., combined chemotherapy and radiation). In addition to persistent feelings of tiredness, some women experience ongoing sexual side effects following their treatment.

Sexual functioning. Cancer treatments that disturb the normal hormone balance can lessen sexual desire as well as cause physical symptoms related to sexual functioning (ACS, 2011). Pain during intercourse is the most common problem for women who have undergone breast cancer treatment. Often, it is related to changes in the vagina's size or moistness, which may occur after pelvic surgery, radiation therapy, or treatment that has affected a woman's hormones (ACS, 2011). Huber, Ramnarace, and McCaffrey (2006) conducted a meta-analysis across five studies that looked at sexuality and intimacy issues among women with breast cancer and found women and their partners may experience lifelong sexual dysfunction after diagnosis. A multifaceted study conducted by Meyerowitz and colleagues (1999) surveyed 863 breast cancer survivors to examine their sexuality following treatment. One-third of the women reported that breast cancer had a negative impact on their sex life, and more revealed negative changes in at least some areas of their sexual health. Women who were most likely to report a negative impact on their sexual health following cancer were those who experienced changes in their hormonal status as a result of treatment, had relationship problems with their partner, and experienced difficulty with vaginal dryness (Meyerowitz, Desmond, Rowland, Wyatt, &

Ganz, 1999). Another study revealed that among sexually active breast cancer survivors who were one to five years post-diagnosis and in a partnered relationship, the most important and consistent predictors of sexual health were presence or absence of vaginal dryness, emotional wellbeing, body image, quality of the partnered relationship, and whether a woman's partner had sexual problems (Ganz, Desmond, Belin, Meyerowitz, & Roland, 1999). Studies have shown the effect breast cancer treatment can have on women's sexual functioning. Cancer treatment may also result in women experiencing difficulty with memory and cognition abilities

Memory and cognition. One common complaint following chemotherapy treatment is that patients may notice changes in their cognitive functioning. The American Cancer Society (2010d) highlighted for years that cancer survivors have worried about, joked about, and been frustrated with the mental cloudiness they experience before, during, and after chemotherapy. The described mental fog is commonly and colloquially referred to as "chemo brain." Bender and colleagues (2006) noted some cognitive changes related to cancer are minor and reversible, whereas others are more noticeable, and not reversible. Cognitive changes are described as happening suddenly (acute onset) or gradually being noticed over time (gradual onset). Although patients have noticed mental symptoms for some time, only recently have studies started to explore this phenomenon. The first longitudinal study was published by Ahles and colleagues (2002), exploring cognitive deficits of chemotherapy among long-term survivors of breast cancer and lymphoma who had been treated with standard doses of systemic chemotherapy or local therapy only. The study revealed that systemic chemotherapy can have a negative impact on cognitive functioning as measured by testing and on memory as measured by self-report from participants (Ahles et al., 2002).

Since this initial study, a fair amount of research has been done, including a study by Hess and Insel (2007) who developed a conceptual model of chemotherapy-related changes in cognitive functions. Bender et al. (2006) conducted a more detailed study than Ahles and colleagues, examining cognitive function changes over time in women with breast cancer who did or did not received adjuvant therapy. They found that women

who received chemotherapy and Tamoxifen exhibited deterioration on measures of visual memory and verbal working memory and reported more memory complaints. Women who received chemotherapy alone also showed a decrease in their verbal working memory ability, whereas the control group showed an improvement in cognitive functioning (Bender et al., 2006). Among breast cancer survivors, research has shown that some cancer medications can cause changes in the brain. Imaging tests have shown that after chemotherapy, some patients have smaller brain size in the parts of the brain that deal with memory, planning, putting thoughts into action, monitoring thought processes and behavior, and inhibition (Inagaki et al, 2007; Silverman et al., 2006).

To gain a better understanding how "chemo brain" may affect the lives of cancer survivors, ACS (2010d) describes examples of cognitive difficulties survivors may experience:

- forgetting things that they usually have no trouble recalling-- memory lapses
- trouble concentrating--they cannot focus on the task at hand
- trouble remembering details like names, dates, and sometimes larger events
- trouble multi-tasking, such as answering the phone while cooking, without losing track of one of them decreased ability to do more than one thing at a time
- taking longer to finish things, slower thinking and processing
- trouble remembering common words, can't finish a sentence as a result of having difficult being able to retrieve the right words

Emotional concerns. In addition to some of the common physical symptoms that persist for months or years following treatment, emotional concerns can also arise and linger following treatment for breast cancer.

The complexity of primary breast cancer treatment, information overload, the immediate need to make critical decisions about treatment, and the vulnerability associated with a cancer diagnosis can all threaten the emotional wellbeing of the woman. In addition, need for treatment that may last for months can cause disruption in social activities as well as decrease a cancer survivor's ability to plan and multitask,

exacerbating the physical and emotional toll experienced by breast cancer patients. Almost three decades ago the Psychological Aspects of Breast Cancer Study Group (PABC) found over time the dysphoria of being diagnosed with breast cancer lessened; emotions seemed to stabilize within a year following initial diagnosis (PABC, 1987). Psychosocial concerns including specifically fear of recurrence and distress, have been identified as common emotional concerns during breast cancer survivorship.

Psychosocial concerns. Recently, the National Cancer Policy Board of the Institute of Medicine (IOM, 2004) examined the psychosocial consequences of breast cancer among women and found the most common concerns were fear of recurrence, body image disruption, sexual dysfunction, treatment related anxieties, intrusive thoughts about illness/persistent anxiety, difficulty with marital/partner communication, feelings of vulnerability, and existential concerns regarding mortality (Boyle, 2006; Ganz, 2008; IOM, 2004;). Psychosocial concerns among early-stage breast cancer survivors included similar findings related to emotional distress, fear of recurrence and anxiety, whereas changes in mood and feeling sad or blue were found to diminish over time (Cappiello et al., 2007). Factors that placed women at higher risk for psychosocial distress included younger age (less than 50 years old), preexisting mental illness or psychological distress, comorbid conditions, and limited social support (Ganz, 2008). Although there are a host of psychosocial concerns, the emotional concern most commonly experienced along the breast cancer continuum is fear of recurrence.

Fear of recurrence. Fear of recurrence and anxiety regarding postoperative treatments accounted for more than 65% of responses to a question inquiring about concerns among women newly diagnosed with breast cancer (Stephens, Osowaski, Fidale, & Spagnoli, 2008). When women were asked about their emotional responses during the recovery phase, the most frequent psychological concern was fear of recurrence (Cappiello et al., 2007). Women across age groups (27 to > 65 years) were found to have moderate fears of recurrence and development of a second cancer (Cimprich, Ronis, & Martinez-Ramos, 2002). Even years after initial diagnosis, Bower et al. (2005) found 40% of breast cancer survivors sampled within five years post-

diagnosis reported persistent concerns about cancer recurrence. An earlier study by Mast (1998) found among a sample of women who completed treatment for breast cancer, fear of recurrence was associated with emotional distress. Along with fear of recurrence, distress can often occur following a diagnosis of breast cancer and continue on after completing treatment.

Distress. The National Comprehensive Cancer Network Clinical Practice Guidelines define distress as "unpleasant feelings or emotions that may interfere with your ability to cope with cancer, its physical symptoms, and its treatment" (2010b, p. 5). The term *distress* covers a range of feelings, from powerlessness, sadness, hopelessness, and fear to depression, guilt, anxiety, and panic. When considering cancer survivorship, *psychological distress* refers to a broad range of affective and cognitive concerns that go beyond psychiatric diagnosis of major depressive illness or anxiety disorders. Cancer-specific concerns range from fear of cancer recurrence, to more generalized symptoms such as worry, trouble sleeping, and feeling anxious when going to the doctor (Ganz, 2008). Gallagher, Parle, and Cairns (2002) found 43% of women were likely to experience anxiety or depressive disorders at some time within the first six months after receiving a diagnosis of breast cancer. Contributing variables found to be predictors of psychological morbidity within the first six months post diagnosis included age under 50, having children under 21 years, psychiatric history, and poor social support (Gallahger, Parle, & Cairns, 2002).

Although some psychosocial concerns (including fear of recurrence and distress) of breast cancer survivors were identified in the 2004 IOM report, the barriers that are keeping the psychosocial needs of patients from being met have not been adequately elucidated. Kaplan (2008) highlighted some of the barriers to meeting the psychosocial needs of survivors, including the following (p. 989):

- fragmented provision of care and lack of coordination between different treatment settings
- psychosocial services have not followed the shift from inpatient care to outpatient centers and private offices

- limited time during patient visits
- stigma associated with seeking mental health services
- inadequate health insurance coverage
- failure of healthcare provider to ask about emotional distress
- lack of simple, rapid screening tools for emotional distress
- lack of knowledge of clinical practice guidelines for managing distress
- lack of awareness of psychosocial resources in the community

The barriers identified speak to why survivors are often left to fend for themselves when faced with these types of physical and emotional challenges following treatment completion. Among breast cancer survivors, age at diagnosis appears to influence the types and severity of physical and emotional challenges.

Age at Diagnosis: Younger versus Older Survivors

Most breast cancers occur in women older than 50 years of age (about 75% of cases) (ACS, 2010b). Research has begun to examine the impact of age-related changes in breast cancer survivors. Breast cancer affects women in all adult stages of life. Adult developmental life stages encompass certain biological, personal, and social life goals and tasks that may be disrupted by the diagnosis of breast cancer. Mages and Mendelsohn (1979) are known for their pioneering work using a developmental life-stage perspective to describe how cancer affects people's lives and adaptation in younger, middle, and older adulthood. Their clinical assessments have suggested that for older patients the discovery of cancer can lead to an acceleration of psychosocial aspects of aging, such as premature disengagement from external commitments, increased dependency, and the need to review and integrate the past. They also reported that older patients seem to face cancer with less anger than younger patients and speculated the latter felt they have not yet had a chance to live a full life (Mages & Mendelsohn, 1979).

Rowland (1989) is credited with formulating adult developmental stages that are pertinent to the diagnosis of breast cancer. These developmental stages are classified as the mature adult (31-45 years), the adult in middle age (45-65 years), and the aging adult (>65 years). Within each adult life stage Rowland (1989), reported that individuals

encounter a number of physical, psychological, psychosexual, and social tasks. For the mature adult, life often involves the attainment of personal, social, and career goals, which may include raising children and establishing family, career, and social roles. The middle age adult is typically faced with the need for adaptation to a range of physical, emotional, and social life changes. Such adaptations may relate to hormonal changes in menopause, role reversals between parents and children, and the peaking of careers. Lastly, the aging adult tends to be confronted with changes in the work roles with retirement, diminished physical ability and performance, and the possible loss of a spouse or friend.

One study explored the impact of developmental life stages on quality of life among breast cancer survivors. Cimprich et al. (2002) conducted a cross-sectional study that examined how life stage (younger [27-44 years], middle [45-65 years], and older [> 65 years]) at diagnosis could influence current quality of life among long-term breast cancer survivors. They found that older women diagnosed with breast cancer had poorer overall physical health, felt less useful in life, experienced more uncertainty about the future, and made fewer positive life changes following their diagnosis and treatment completion. Younger women, on the other hand, had more difficulty with reproductive issues (i.e., fertility and menstrual changes); more psychological distress related to their diagnosis and treatment, changes in appearance and self-concept; and more family distress; and experienced a greater impact on their sexuality. Interestingly, women who received a diagnosis at midlife (45-65 years) tended to have better physical status than younger or older women, more happiness than younger women and better overall quality of life (Cimprich et al., 2002).

The point in time when breast cancer occurs is an important consideration because specific adult developmental tasks are occurring concurrently that can affect a woman's quality of life differentially depending on life stage. A diagnosis of breast cancer can be a life-changing event that may compromise a woman's ability to deal effectively with relevant life stage responsibilities and to handle expected tasks that are necessary for daily life roles. Studies have begun to explore the interaction of age at diagnosis, an

approximation of life stage, and how a breast cancer diagnosis can have both positive and negative psychosocial consequences that affect recovery and long-term quality of life outcomes.

Younger breast cancer survivors. Based on reviewed literature, younger women with breast cancer appear to have different concerns than older women. Younger survivors experience the adverse consequences of their illness and treatment for a longer period of time and may suffer additional role limitations associated with employment, family life, and activity level. An important dynamic related to developmental stages, such as having family responsibilities and being premenopausal, are additional issues often faced by young breast cancer survivors. Dunn and Stegina (2000) found young women diagnosed with breast cancer often go through a 'why me' phase early after their initial diagnosis as the realization of the severity of the illness becomes a reality. Coyne and Borbasi (2009) conducted a qualitative study with six young women (ages 28 to 45 years) with a diagnosis of breast cancer within the past 12 months. Participants identified three time periods as particularly challenging during diagnosis and treatment. Following their diagnosis women recalled grieving life aspirations they felt were suddenly lost. During the treatment process women acknowledged they felt as though they had to 'go it alone' to keep the family routine as normal and consistent as possible. Lastly, young participants recalled the ups and down of treatments and how this influenced their physical and psychological wellbeing. The author concluded from the young women's shared experiences that the aggressive nature of breast cancer, unyielding treatment schedules, and physical side effects compounded their overall distress (Coyne, 2009).

It has been well documented that younger women are more likely to be diagnosed with a more biologically aggressive cancer and tend to need multimodal cancer-related treatments (Sariergo, 2010; Yankaskas, 2006). Undergoing multiple types of breast cancer treatment modalities tends to influence young women's physical and psychological adaptation (Sammarco, 2003). In addition to multiple roles and responsibilities young women typically carry during this phase of life, the treatment regime immediately after diagnosis was shown to induce significant distress in young

women (Sammarco, 2001). The demands of breast cancer treatment and demands of family life have been found to have significant physical and psychological sequelae for younger women as compared to older women (Mosher & Danoff-Burg, 2005).

Janz et al. (2007) found younger age at diagnosis was associated with more severe symptoms following breast cancer treatment completion. Dow and Lafferty (2000) looked exclusively at younger (less than 45 years old) breast cancer survivors who underwent breast-conserving surgery (BCS) and radiation therapy (RT) as their treatment regimens. The study examined changes in quality of life, psychosocial adjustment and survivorship issues from the start of RT to six months later. Younger breast cancer survivors were found to have a decline in their quality of life from the start of RT until the midpoint (3 months) when a gradual incline was observed at six months following RT. Social and sexual adjustment was also found to decline from the start of RT and remain six months following RT completion. Another study explored the concerns of younger women (< 50 years) soon after diagnosis and again five years following their diagnosis and treatment for breast cancer (Bloom, Stewart, Chang, & Banks, 2004). A significant decrease in emotional support and the size of one's social network was reported at five years following treatment completion. Interestingly, no significant changes in employment status, martial/partner status, sexual activity, sexual problems, self-esteem, and attendance at religious services or frequency of prayer were observed. The authors found overall good quality of life over time was associated with fewer chronic conditions and a smaller decrease in emotional support (Bloom et al., 2004).

Older breast cancer survivors. It has been proposed by researchers that older survivors may have an increased psychological resilience to breast cancer diagnosis due to their life stage than younger women. Contributing factors to resilience may be the fact that threats to sexuality, fertility, career, and ability to care for young children are minimized in older survivors (Mosher & Danoff-Burg, 2005). Perkins and colleagues (2007) examined 127 women, 70 years old and above, with a history of at least one year's survival of breast cancer. Results supported the importance of psychosocial resources as protective factors for older women coping with breast cancer survivorship. Interestingly,

although age was a predictor for depression, it accounted for little variance. The study concluded that type of surgery received, whether chemotherapy was a part of the treatment regimen, or time from initial diagnosis were not significant predictors of life satisfaction, depression, or general health perceptions of older breast cancer survivors (Perkins et al., 2007). Previous research has also found that age and treatment regimens do not generally play a significant role in overall quality of life in older breast cancer survivors (Ganz et al., 2003; Mandelblatt et al., 2003). The authors proposed that the passage of time from initial diagnosis and treatment may minimize or stabilize the physical and psychological impact breast cancer treatment received can have on a long-term basis (Perkins et al., 2007). Using the same sample population as Perkins and colleagues (2007), Robb et al. (2007) examined quality of life among 127 older breast cancer survivors compared to 87 older women with no prior history of breast cancer. Older survivors did not report more depressive symptoms or anxious mood than the comparison group, but did endorse lower scores in relation to psychosocial wellbeing (including life satisfaction, mastery, and spiritual wellbeing), and reported more depressed mood and days affected by fatigue. These findings suggest a need for greater attention to promoting functional and psychological wellbeing among older breast cancer survivors (Robb et al., 2007).

Ganz and collegues (2003) examined health-related quality of life among 691 breast cancer survivors, 65 years and older. Fifteen months following breast surgery, the authors observed significant declines in physical and mental health of older women; however, over time, cancer-specific psychosocial quality of life measure scores improved. The authors concluded that older women with impaired physical functioning, mental health, and emotional social support following surgery had poorer self-perceived health and psychosocial adjustment one year later (Ganz, et al., 2003). These findings speak to the increased need to create interventions to address the physical and emotional needs of older breast cancer survivors. Another study by Mandleblatt and colleagues (2003) surveyed 732 older breast cancer survivors (67 years and older) who were three, four, and five years post-treatment for stage I and II breast cancer about post-treatment

quality of life and satisfaction. They found women who felt perceived high levels of ageism or felt they had no choice of treatment experienced more bodily pain, lower mental health scores, and less general satisfaction. The research indicated having a choice of treatments and perception of care on the basis of age were associated with better long-term general physical and mental function, impact of cancer, and overall satisfaction (Mandleblatt et al., 2003).

Shared and unique needs of older and younger breast cancer survivors. Although younger and older breast cancer survivors appear to vary in their survivorship experiences, both have common and different needs following treatment completion. An Australian study by Thewes, Butow, Girgis, and Pendlebury (2004) explored the shared and unique needs of younger versus older breast cancer survivors. Fatigue, breast and arm pain, and problems with lymphedema were the most commonly reported late effects of treatment by both younger and older women. Both younger and older survivors identified the ongoing need for emotional and practical support from family and friends, the need to access professional counselors and the need to learn coping strategies to deal with fear of recurrence and manage day-to-day stressors (Thewes et al., 2004). As a result of the identified physical and emotional symptoms breast cancer survivors experience and some of the barriers to service delivery, efforts have been made to highlight the needs of breast cancer survivors.

Needs of Breast Cancer Survivors during the Survivorship Continuum

Importance of identifying needs during survivorship. The emotional stress brought about by a cancer diagnosis often causes patients and their families to be faced with coping with the stresses induced by physically-demanding treatment and at times the permanent health impairments (e.g., disability, fatigue, pain) that result long after treatment is completed. These effects contribute to emotional distress and mental health problems among cancer survivors, and together can lead to substantial social problems, such as the inability to work, and reduced income (IOM, 2007). Quality of life following a breast cancer diagnosis is influenced by how and when the disease is diagnosed, the treatment, and the manner in which care is delivered. Many survivors have reported

dissatisfaction with the amount and type of information they are given about their diagnosis, available treatment, and ways to manage their illness and health. The healthcare community is becoming increasingly aware of the importance of addressing the physical, psychological, and social problems among cancer survivors in order to provide good quality healthcare and promote better overall health. Furthermore, the psychosocial impact of breast cancer is recommended to be understood in the context of other issues that affect women's coping, quality of life, and wellbeing, such as socioeconomic and cultural factors, social support, access to healthcare, and comorbidities and other life crises (IOM, 2004). A number of studies have identified the importance and benefits of meeting the unmet needs of cancer survivors.

The presence and absence of anxiety and/or depression can impact survivors' needs and their ability to maintain psychosocial support. Hodgkinson and colleagues (2007b) found a high percentage (86%) of breast cancer survivors with unmet needs experienced high levels of anxiety and depression. A German study examined a large sample (n=1,083) of long-term breast cancer survivors to assess psychological comorbidity and health-related quality of life and its association with awareness, utilization and need for psychosocial support (Mehnert & Koch, 2008). The authors found psychological comorbidity (anxiety and depression) was a significant predictor of less social support. On a more positive note, higher perceived knowledge about psychosocial support was associated with less depression and better social support.

Social support has been shown to influence distress that often affects breast cancer survivors during and following treatment. Alferi, Carver, Antoni, Weiss, & Duran (2001) conducted a longitudinal study that examined distress and different types (emotional, instrumental) and sources (spouse, women family member(s), other family members, friends) of social support measured at pre-surgery, post-surgery, and at 3-, 6-, and 12 month follow-ups. These authors found emotional support from friends and instrumental support from spouse at pre-surgery predicted lower distress post-surgery. Communication may also affect women's emotional wellbeing. Women who rated their

ability to communicate with their physician low were found to have lower levels of emotional health (Sillman, Dukes, Sullivan, & Kaplan, 1998).

To address some of the totalities breast cancer can have on one's emotional and physical wellbeing, a great deal of research has explored various psychosocial interventions within group settings. The 2004 IOM report included a meta-analysis that examined 13 support group interventions that were conducted among early and metastatic breast cancer survivors. Across the studies, group interventions were shown to improve mood, enhance coping, reduce phobias, reduce traumatic stress symptoms, enhance vitality, increase social functioning, reduce severity of psychiatric symptoms, enhance quality of life, and enhance spiritual integration (IOM, 2004).

As indicated from the reviewed research, a host of studies indicate the importance of identifying and working to meet the physical, psychological, and daily living challenges of breast cancer survivors. When examining the needs of breast cancer survivors, identifying the needs during diagnosis, treatment, and following treatment completion is of importance to gaining a better understanding of the needs of breast cancer survivors along the survivorship continuum.

Needs during diagnosis. When women hear the words "you have cancer", many experience fear and disbelief and are immediately concerned with their future, the treatment ahead, and the consequences of the disease for their families. Although most women are unprepared for a cancer diagnosis, they face an array of healthcare providers and are required to make crucial treatment decisions. After an initial biopsy is performed, further evaluation is involved to determine the stage of the disease and prognosis for treatment (IOM, 2004). Women are frequently faced with deciding the type of treatment they will have and where their treatment will be administered. At this phase, women and their support systems are bombarded with information, often leading to information overload and making it difficult to make sound decisions. During the diagnostic process, the patient is also responsible for choosing a medical team to provide and coordinate her care (IOM, 2004). The medical team may view the complexities of treatment decisions as routine, while patients are faced with having to make crucial

decisions related to issues about which they have little knowledge or background information. Sound delivery of vital treatment information at this point in the breast cancer continuum is a need that often goes unmet. In fact, the IOM (2007) report that focused on cancer for the whole patient identified that many people living with cancer reported dissatisfaction with the amount and type of information they were provided about their diagnosis, available treatments, and ways to manage their illness and healthcare.

Stephens and colleagues (2008) sought to identify the educational needs and concerns of newly diagnosed breast cancer patients following surgery. Emotional, social, and physical limitations were identified as the most important topic areas for educational needs when dealing with a breast cancer diagnosis. In addition, Stephens and her colleagues describe the importance of adequate information and resources for women newly diagnosed with breast cancer. As many as 40 percent of participants identified the importance of early education with an emphasis on social, emotional, physical, and spiritual support. Arora, Finny Ritten, Gustafson, Moser, and Hawkins (2007) evaluated the helpfulness of informational, emotional, and decision-making support received by newly diagnosed breast cancer patients from their family, friends, and healthcare providers. Women were assessed at baseline which was an average of two months post-diagnosis and at five months post-baseline. The researchers found that closest to the value of diagnosis, family and healthcare providers helped the majority of women by providing helpful informational (providers only) and decision-making (providers and family) support, as well as emotional support. As women moved further from initial diagnosis, all types of support among family, friends, and healthcare providers decreased significantly at 5-month follow-up.

Needs during treatment. Once a treatment plan has been decided, women may experience some relief of anxiety and distress because a plan is in place to treat the breast cancer; however, new fears often arise in anticipating and receiving treatment. Two women with the same type of breast cancer diagnosed at the same stage may have totally different reactions and side effects to treatment, depending on their physiology and

perceptions of their condition. Their ability to function during the course of radiation therapy or chemotherapy may be profoundly affected by presence or absence of a variety of factors. These factors include, but are not limited to, physical side effects, fear about the future, questions about the possibility of recovery, financial concerns, and special pressures on relationships (Cukier et al., 2005). Due to the numerous contributing factors, it is important to identify the needs women experience during treatment.

A qualitative analysis of younger survivors (< 50 years) stressed the need for education about breast cancer treatment and the need for second opinions (Bloom et al., 2004). Another qualitative study utilizing focus groups of younger survivors found that women with breast cancer felt having as much information as possible was a means for gaining control over their medical condition and its treatment (Allen, Petrisek, & Laliberte, 2001). In addition, the need for educational information preparing survivors for the transition from treatment to survivorship has been noted (Allen et al., 2001).

Needs following treatment completion. Survivors of breast cancer continue to experience educational and emotional needs following treatment completion. Cappeillo and colleagues (2007) conducted a qualitative study to assess information and support needs of women at three, six, and 12 months following treatment for early-stage breast cancer. Women were asked how well they were prepared for the transition from treatment to survivorship. Nearly half (45%) reported they had not received any information about what to expect. The majority of women in the study stated they would have liked to receive more detailed information about what to expect during the transition period. In addition, women were asked to describe major challenges they experienced during the first year after treatment completion. A theme that emerged based on their responses was the struggle to return to the life they led before their breast cancer diagnosis. Overall, the study revealed women experienced additional educational needs that included the need for information about persistent treatment side effects, emotional distress, and lifestyle changes (Cappiello et al., 2007).

The absence of ongoing disease did not imply an absence of cancer-related supportive care needs among an Australian sample of breast cancer survivors. In

addition, time since diagnosis was not associated with lower needs (Hodgkinson et al., 2007b). In fact, Hodgkinson and colleagues (2007b) found high rates of anxiety and supportive care needs were reported among breast cancer survivors up to 10 years post-treatment. Gray and his colleagues in Ontario, Canada relied on nine focus groups to identify information needs and preferences of breast cancer survivors four years or more after initial diagnosis. Two broad themes emerged: 1) the context within which women sought information, and 2) the content of information that was desired and sought. Some of the themes related to context included the ongoing impact of the disease experience and continued fear of recurrence; lack of information and understanding about treatment; and concerns related to communication with healthcare providers. Themes related to content included lack of information about follow-up protocols, Tamoxifen, detecting symptoms of recurrence, prevention for daughters, and lifestyle changes (Gray et al., 1998). The role healthcare provides play in service delivery is thus clearly vital to meeting the unmet needs of breast cancer survivors.

Healthcare Providers' Roles Following Treatment

After a review of the literature, Vivar and McQueen (2002) found that breast cancer survivors experience informational and emotional needs during long-term survivorship and that women's needs are often unmet by oncology teams. Patients often rely on their physicians to provide them with social, interpersonal, informational, and decisional support (Arora, 2003). Sadly, patients reported their care providers often failed to communicate information about their diagnosis and treatment options in an understandable fashion. Concurrently, patients stated their providers did not understand their psychosocial needs, did not consider psychosocial support to be an integral part of care, were unaware of psychosocial healthcare resources, and failed to recognize, adequately treat, or refer patients to services that would be helpful (IOM, 2007).

Based on these shortcoming and the identified needs of cancer survivors, it is important for oncology and primary care providers to be prepared, to address, and support the range of physical and emotional concerns, as well as the informational and supportive needs patients experience along the breast cancer treatment continuum. The

IOM (2004) advocated for oncologists and other primary care providers to plan for and be prepared to evaluate and help patients with the range of psychosocial issues that arise along the breast cancer treatment continuum. Physicians' communication behavior has been shown to have a positive impact on patient health outcomes. Therefore, the patient-physician interaction plays a significant role in the cancer care delivery system (Arora, 2003).

Communication challenges with providers. Bloom and colleagues (2004) conducted interviews with 185 women who were under 50 years old at diagnosis and were cancer-free five years later. Of the survivors interviewed, more than one-third (37%) reported having difficulty communicating with their physicians. Specifically, some women reported feeling as though they were not listened to and others felt their physicians were insensitive to the psychological aspects of having breast cancer (Bloom et al., 2004). Lerman and colleagues (1993) had similar findings when they evaluated perceptions of patients with breast cancer of their medical interactions with providers. Of 97 participants, 84% reported having difficulty communicating with their medical team. At the 3-month follow-up, patient-reported communication problems were associated with increased anxiety, depression, anger, and confusion. Communication problems were also reported by breast cancer survivors who experienced more distress, were less optimistic, and felt more helpless about their disease (Lerman et al., 1993). Similarly, younger breast cancer survivors indicated that doctor-patient communications concerning detection, diagnosis, and treatment decision-making were the most problematic aspects of their experiences with cancer (Allen et al., 2001).

A Canadian qualitative study (Gray et al., 1998) of breast cancer survivors found that based on their experience with physicians and other health professionals, women were afraid to raise concerns about "worrisome symptoms" for fear of being seen as neurotic or malingering. In the same study women expressed satisfaction with and relief when they were able to access information through an empathic professional. A study in Australia found both younger and older survivors stressed the importance of emotional support and reassurance from physicians and medical staff during follow-up visits. A

small number of younger women voiced the perception that physicians were only interested in their physical recovery, and as a result they were reluctant to discuss emotional issues (Thewes et al., 2004). Findings such as these speak to the importance of patient-provider communication; yet, service providers face challenges when communicating with patients about cancer survivorship topics. Communication and patient-provider challenges in general tend to be even greater for patients and providers in rural areas.

Challenges of Rural Providers

Burg, Grant, and Hatch (2005) examined the challenges faced by rural and urban primary care physicians (PCP) when caring for cancer survivors. PCPs noted the side-effects of cancer and its treatment and limited access to supportive care services were frequent problems for their patients. In addition, the most challenging aspect of caring for survivors was the promotion of cancer-related risk reduction behaviors. Based on a meta-analysis that focused on rural breast cancer survivors, medical personnel were considered one of the main sources of support for patients during primary treatment (Bettencourt, Schlegel, Talley, & Molix, 2007). The authors suggested a need to facilitate information-sharing and cooperation among oncologists and general practitioners in rural areas. The importance of keeping rural and general practitioners knowledgeable about current breast cancer treatment recommendations was expressed (Bettencourt et al., 2007). In addition, when assessing unmet needs of rural breast cancer survivors, the authors identified the need to coordinate efforts among multiple providers of rural survivors as well as to facilitate communication between patient and provider (Wilson, Anderson, & Meischke, 2000). These studies speak to the challenges providers face when serving rural breast cancer survivor residents from a provider's perspective. Additional challenges are related to the rural lifestyles of breast cancer survivors.

Challenges of Rural Breast Cancer Survivors

Living in rural areas, where treatment services are not available, creates additional challenges for women who are faced with traveling away from their home to receive treatment. The American Psychological Association's Committee on Rural Health

identified rural women were often faced with different treatment options than women in urban areas (APA, 2000). For example, women diagnosed with breast cancer in rural areas of Mid-Missouri were less likely to be offered breast conserving treatment options and were more likely to undergo radical mastectomy when compared to urban women, regardless of the availability of other conservative procedures.

A study conducted in rural Washington explored ways to improve the lives of rural breast cancer survivors and to expand existing knowledge of breast cancer survivorship. Findings showed regardless of stage at diagnosis, there was a continual need for more education about breast cancer and more emotional support after diagnosis for rural women (Wilson et al., 2000). Across international and national studies, rural women desired greater access to health-related information during and after treatment. Medical personnel were identified as being knowledgeable and capable of delivering the needed information services identified by rural breast cancer survivors (Bettencourt et al., 2007). Although numerous studies have been conducted to explore the needs of rural breast cancer survivors nationally, limited research has been conducted to evaluate the unique needs of female breast cancer survivors living in urban and rural areas of Alaska. Prior to identifying the unique challenges of Alaskan breast cancer survivors, it is of importance to identify the impact of breast cancer in Alaska.

Breast Cancer in Alaska

According to the Alaska Department of Health and Social Services (DHSS) (2006), cancer is the leading cause of death in Alaska, accounting for 31% of deaths since 1993. Female breast cancer ranks second highest for incidence and mortality compared to all other cancers, eclipsed only by lung cancer. Alaska's incidence rate for female breast cancer (134.3 per 100,000) is higher than the national rate of breast cancer incidence (131.3 per 100,000) (DHSS, 2008). Statewide, an average of 319 Alaskan women were diagnosed annually with breast cancer between 1996 and 2004 and an average of 49 Alaskan women die each year from the disease (DHSS, 2008). The American Cancer Society estimated that in 2009 370 women will be diagnosed with

breast cancer in Alaska and within that same year, 60 are estimated to die from the disease (ACS, 2010b).

In Alaska, across a 4-year time period (2002-2006) approximately 128.9 (per 100,000) women of European American descent were diagnosed with breast cancer and of those 22.0 per 100,000 died. African American women had lower incidence rate with an estimated 83.4 (per 100,000) breast cancer cases diagnosed between 2002 and 2006. During the same 4-year time span African American women's mortality rate was not able to be calculated due to fewer than 16 deaths in Alaska (ACS, 2010b). However, in previous years (2000-2004) African American women in Alaska had a higher mortality rate of 30.0 deaths per 100,000 during a 4-year time span (ACS, 2007). Breast cancer rates among Alaska Natives ranked highest (136.7 per 100,000) when compared to other Native American women in the US (62.8). Between 1996 and 2004, 2,246 cases of breast cancer were diagnosed among White Alaskans in comparison to 446 cases diagnosed among Alaska Native women (DHSS, 2008).

Barriers to Services for Breast Cancer Treatment in Alaska

In Alaska, rural residents, the majority of whom are Alaska Native, encounter unique challenges when faced with breast cancer diagnosis, treatment, and post-treatment care. Challenges for rural Alaskan cancer patients include gaining access to needed treatment and traveling away from residences and loved ones. Rural cancer survivors face unique issues, including returning to their communities after having been away for extended periods of time, difficulty traveling long distances for continuing care, inability to hunt and fish or obtain subsistence foods as before, and lack of support groups in villages (Alaska Native Tribal Health Consortium Cancer Program [ANTHC], 2006).

To better understand why these challenges arise for rural cancer patients, one needs to understand the unique challenges rural Alaskans face in attempting to access needed healthcare given the geographic vastness and remoteness of the state. Alaska's geographical layout presents several barriers to providing cancer prevention, early detection, and cancer care services. In 2005, Alaska's estimated population was 664,000, with approximately 30% of the population living in rural areas. Although Alaska's

population ranks 48th of the 50 states, Alaska's landmass measures over twice the size of Texas (the next largest state), covering roughly 586,412 square miles of mainly roadless terrain. According to the U.S. Census, Alaska has 229 federally recognized tribes and approximately 119,241 Alaska Native residents. Forty-one percent of Alaska's population resides in Anchorage and 79% of the population resides in the six largest census areas: Anchorage, Fairbanks, the Kenai Peninsula, Ketchikan, the Matanuska-Susitna Borough, and Juneau – the state capital of Alaska. Many Alaskans travel 200 to 500 miles for healthcare services, including hospital care (DHSS, 2006). Of the state's population, 72% reside in areas connected by the highway system. The remaining population lives in roadless areas where obtaining access to urban centers or the lower 48 states is accomplished by way of air, boat, or snow machine. Residents of rural areas are frequently faced with the challenge of travel being difficult, expensive, and hazardous.

The two urban cities of Fairbanks, Anchorage, and Matanuska-Susitna Valley are the only locations in Alaska that provide chemotherapy, radiation therapy, and surgical treatment options in one location. At this time, cancer treatment clinical trials are only available in Anchorage (aside from seeking services in the lower 48 states). Due to the lack of local cancer care services, Alaskans from rural areas are required to travel from outlying communities to Anchorage or Fairbanks or outside the state. Thus, a significant number of cancer patients in Alaska travel for cancer treatment services (DHSS, 2006). Geographic barriers, distance, lack of transportation and inadequate funding affect access to medical and mental health services.

Travel outside of Alaska or to urban areas within the state for cancer patients and their families is an added expense and significant burden when treatment can take weeks to months. A number of local resources are working toward lessening the burden of travel expenses for patients and their families and supporting treatment options that keep patients as close to their community as possible (DHSS, 2006). To identify the increasing need for cancer treatment facilities in the state of Alaska, cancer registries have been tracking rates of cancer statewide since 1995 and among Alaska Native residents since 1969. Although some Alaskan breast cancer survivors have access to

cancer care services, others in Alaska have limited access to needed healthcare services that could increase their odds of survival. The ability to identify the needs of breast cancer survivors is the key to providing higher quality care. Little work has been done to identify the needs of Alaska women who have faced breast cancer and even less information is available about the needs of rural versus urban survivors. However, better understanding these women's needs in the unique context of living in Alaska is crucial to the development of more effective systems of care for breast cancer survivors.

Assessing Unmet Needs of Breast Cancer Survivors in Alaska

The method of conducting needs assessments provides a venue to better understand how to provide effective services to a specific population (Soriano, 1995). Needs assessments have been found to be beneficial for identifying high-risk groups that may be responsive to interventions and utilization of healthcare services (Bonevski et al., 2000). As discussed above, needs assessments have been completed for various groups of breast cancer survivors in the US and other countries (including Australia and Canada). Hodgkinson and colleagues (2007b) conducted a needs assessment specific to breast cancer survivors to assess their supportive care needs two and 10 years post-diagnosis. Mayer and Grober (2006) conducted a breast cancer needs assessment specific to women with advanced-stage breast cancer. Another needs assessment specific to breast cancer was conducted by Thewes and colleagues (2004) with the purpose of identifying the information, medical communication, and psychological needs of younger breast cancer survivors. Their findings were detailed above and inform the current study, which will focus on a needs assessment of women in Alaska who have survived breast cancer.

Goals and Overview of the Current Study

Due to the high incidence rates of women diagnosed with breast cancer each year and the increasing number of survivors, it was deemed important to examine unmet needs of breast cancer survivors living in Alaska. Breast cancer survivors themselves are most knowledgeable about satisfaction with cancer-related services and their physical, psychological, and daily living challenges on a short-term or long-term basis. Survivors

are the experts in identifying gaps in services during and following treatment. Additionally, healthcare providers play a pivotal role in effective service delivery to breast cancer patients along the survivorship continuum. Due to the important role of healthcare providers, it was viewed as beneficial to gain their perspectives on the needs of breast cancer survivors in Alaska and on strategies for meeting these needs effectively and comprehensively. Healthcare providers are in the unique position of being able to advocate for additional services needed to address the challenges faced by breast cancer survivors in Alaska.

The purpose of this study was to gather data about the needs of Alaskan breast cancer survivors based on the continuum of breast cancer care. In doing so, the study strived to bring awareness to and acknowledge the physical, psychological, and daily living challenges of cancer diagnosis and treatment for breast cancer survivors. The research aimed to identify survivors' demographics, educational needs, medical care issues, and quality of life concerns. Due to the unique geographic challenges of Alaska's rural areas, through identifying survivorship needs from survivors' and healthcare providers' perspectives, awareness was brought about met and unmet needs of urban and rural Alaskan breast cancer survivors. To meet its goals, the current study drew on an existing needs assessment dataset collected from breast cancer survivors living in Alaska. Augmenting secondary data analyses of this dataset, qualitative methods were employed to gather perspectives from healthcare providers. The utility of mixed research methods for meeting the types of goals identified in this study has been amply documented (Allen et al., 2001; Lerman et al., 1993; Royak-Schaler et al., 2008).

Overall, the current study sought to achieve the following goals using combined quantitative and qualitative methods of research:

1. increase knowledge about the experience of Alaskan breast cancer survivors living in urban and rural areas,
2. increase information about services needed to better meet the needs of women with breast cancer living in Alaska,

3. explore and contextualize providers' perceptions of the needs of breast cancer survivors in Alaska,
4. develop an understanding from healthcare providers as to how the needs of breast cancer survivors in Alaska can be met, and
5. develop recommendations for providers, hospital groups, and key community stakeholders about how to improve services to further meet the needs of breast cancer survivors.

Chapter 3 Research Methods

A mixed method approach was used to better understand the needs of breast cancer survivors in Alaska. Mixed methods (using both qualitative and quantitative methods within the same research study) have been utilized to identify informational support and healthcare service needs among those newly diagnosed with breast cancer (Dubois & Loiselle, 2008). Qualitative methods (Davis, Girgis, Williams, & Beeney 1998; Gray et al., 1998; Wilson et al., 2000) and quantitative methods (Girgis, Boyes, Sanson-Fisher, & Burrow, 2000) have been employed to assess needs of rural breast cancer survivors, but little research exploring the needs of breast cancer survivors has utilized a two-phase mixed method design. Due to the inherent strengths of a mixed methods approach, this study utilized an explanatory mixed method approach to achieve the goals outlined in Chapter Two.

In addition to mixed methods, conducting needs assessments provides a venue to better understand effective service provision to a specific population (Soriano, 1995). Needs assessment outcomes can identify high-risk groups likely to benefit from targeted preventive remediation interventions and can facilitate optimal allocation and delivery of limited healthcare resources (Bonevski et al., 2000). Prior breast cancer needs assessments have been conducted using quantifiable measures to assess supportive care needs after diagnosis (Hodgkinson et al., 2007a); information, support, and practical resource needs of women with advanced breast cancer (Mayer & Grober, 2006); and informational, medical communication, and psychological needs of younger breast cancer survivors (Thewes et al., 2004). A mixed method design offers a cohesive method of conducting a thorough needs assessment among breast cancer survivors.

Overview of Mixed Methods Research Approach

A mixed methods research approach was utilized to gain a comprehensive understanding of the needs of breast cancer survivors in Alaska. Integrating quantitative and qualitative methodologies provides a better understanding of a problem than if either approach were used in isolation (Creswell & Plano Clark, 2007). The increased depth and breadth of information drawn from quantitative and qualitative data from multiple

participant groups provides a strong base from which to draw meaningful and valid conclusions, which, in turn, lead to the development of purposeful recommendations intended to address unmet needs of breast cancer survivors in Alaska.

Definition of the explanatory mixed methods design. The purpose of utilizing an explanatory mixed methods design is to use qualitative data to build upon and enhance the results of the quantitative data (Creswell, Plano Clark, Gutman, & Hanson, 2003). A mixed methods, explanatory approach was chosen for the current study due to the wealth of information it can provide. The study design resulted in a three-phase process: 1) Quantitative Research Phase, 2) Qualitative Research Phase, and 3) Integration and Recommendations Phase (see Figure One). Phase One involved conducting secondary data analyses with an existing dataset to examine the services breast cancer survivors received during treatment and follow-up care. Preferred methods of receiving information related to cancer services were also examined. Short-term and long-term physical, psychological, and daily living concerns were identified.

Phase Two entailed an inductive, qualitative approach using semi-structured key informant interviews with healthcare providers who had experience working with breast cancer survivors from rural and urban locations in Alaska. Key informant interview questions for healthcare providers were developed based on results gleaned from Phase One. Qualitative data provided an avenue for exploring healthcare providers' perceptions of breast cancer survivors' needs in Alaska and how to meet these needs effectively and comprehensively. Based on the integration of Phase One and Two data, purposeful policy and treatment recommendations were developed in Phase Three to identify ways to enhance the healthcare system's ability and capacity to meet the needs of breast cancer survivors.

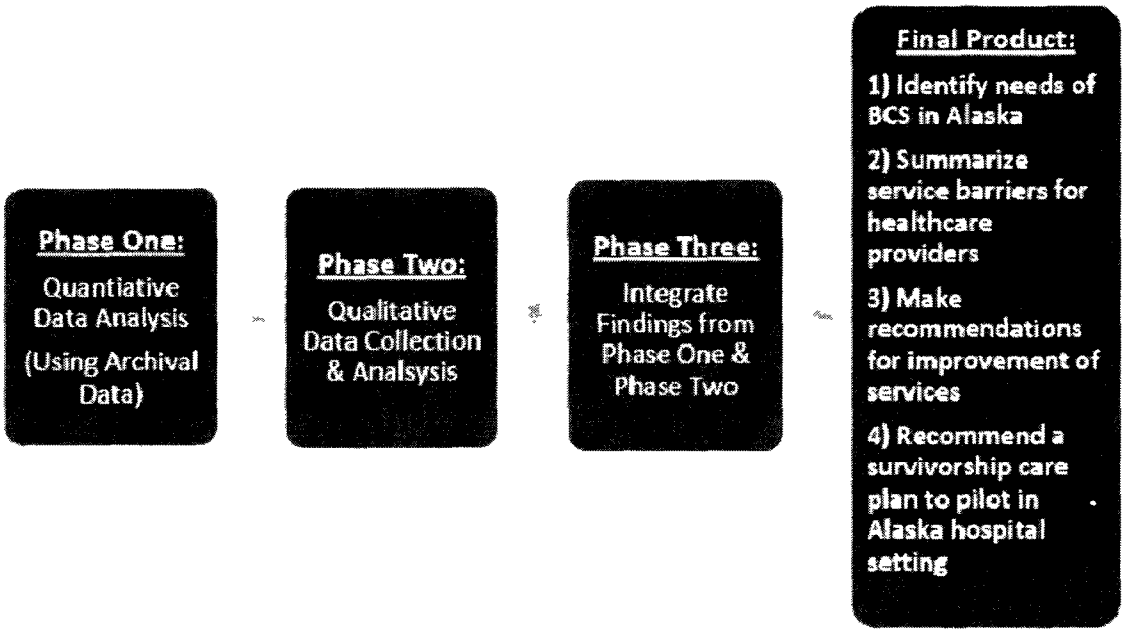

Figure 1. Explanatory Mixed Methods Design

Quantitative Research Phase (Phase 1)

Although considerable research has been conducted to identify unmet needs of breast cancer survivors, no research to date has explored the common and unique challenges of female breast cancer survivors in Alaska. In addition, little is known about whether Alaskan healthcare providers perceive women's unmet needs in the same manner as do breast cancer survivors themselves. It was the purpose of this study to examine needs of breast cancer survivors in Alaska and to gain healthcare providers' perspectives of how unmet needs can be met effectively within and beyond the confines of the current healthcare system. This study began with a quantitative phase (Phase One) that explored the needs of breast cancer survivors living in Alaska within five domains: treatment and services, information needs, physical wellbeing, psychological wellbeing, and daily living challenges.

Background and procedures for use of archival data. Phase One relied on secondary data analyses of a dataset collected for a 2009 study by the University of Alaska Anchorage Center for Behavioral Health Research and Services (CBHRS) in collaboration with Providence Alaska Medical Center. The Alaska Breast Cancer Needs

Assessment Survey (ABCNAS) was administered online and in paper form to female breast cancer survivors across Alaska (CBHRS, 2010). Permission was received from CBHRS and Providence Alaska Medical Center to utilize the dataset for the purposes of the current study (see Appendix F)

Participants

A total of 309 participants were recruited in Alaska over a 6-month period beginning in December 2008. All participants were women, Alaska residents, had a prior diagnosis of breast cancer, and were at least 18 years of age. Average age was 56 years (*SD*=9.59) and ranged from 30 to 86. At the time the survey was completed, women younger than 50 years old accounted for 26.1% of the sample; 73.8% were 50 years and older. With regard to cultural background, 84.8% identified as Caucasian, 7.8% as Alaska Native, 1.6% as American Indian/Native American, and 5.8% as Other. The majority of women resided in urban Alaska (80%), were well educated (with at least some college education), and were employed (at least part-time) with a median annual household income between $70,000 and $79,000 (CBHRS, 2010). Table 7 provides a more detail description of survey participants.

Table 7

Demographic Characteristics of the Sample (N = 309)

Demographic Variables	*M*	*SD*
Mean Age	55.87	9.59
Median Household Income	$70,000 - $79,000	
Education Level (n=304)	*N*	*%*
High school or less	33	10.8%
Some college	80	26.3%
College graduate	192	63.2%
Type of Health Insurance (n=299)		
Private insurance	207	69.2%
Medicaid/ Medicaid/ VA benefits	47	15.7%
IHS or tribal healthcare	15	5.0%
No insurance	6	2.0%
Other	24	8.0%
Employment Status (n=305)		
Working full-time	149	48.9%
Working part-time	43	14.1%
Retired	76	24.9%
Other	37	12.1%
Alaska Residence (n=306)		
Urban (Anchorage & Fairbanks)	228	74.5%
Rural (outside urban areas)	78	25.5%
Primary Ethnicity (n=309)		
Caucasian	262	84.8%
Alaska Native	24	7.8%
Native American/American Indian	5	1.6%
Other	18	5.8%

More than half of the survey participants were diagnosed in the past five years and combined they had a median age at diagnosis of 49. Just over half were diagnosed during early stages (0 and 1) of breast cancer (CBHRS, 2010). Tables 8 and 9 provide a more detailed description of cancer-related characteristics of survey participants.

Table 8

Cancer Related Characteristics of the Sample

Cancer-Related Demographic Variables	*N*	*%*
Years Since Cancer Diagnosis (n=305)		
2 years or less	89	29.2%
3-5 years	85	27.9%
6-10 years	75	24.6%
11-20 years	45	14.8%
More than 20 years	11	3.6%
Median Age at Diagnosis	M = 49.0	
Stage of cancer at diagnosis (n=289)		
Stage 0	36	12.5%
Stage 1	119	41.2%
Stage 2	90	31.1%
Stage 3	36	12.5%
Stage 4	8	2.6%

Table 9

Description of Breast Cancer Survivors by Location of Treatment Options

Location	Diagnosis	Primary Treatment	Complementary Treatment	Psychological Services	Second Opinion
Outside Alaska	22 (7.1%)	28 (9.1%)	26 (8.4%)	12 (3.9%)	53 (17.1%)
Anchorage	212 (68.6%)	226 (73.1%)	135 (43.7%)	62 (20.1%)	64 (20.7%)
Fairbanks	40 (12.9%)	34 (11.0%)	22 (7.1%)	2 (0.2%)	8 (2.6%)
Juneau	5 (1.6%)	3 (1.0%)	4 (1.3%)	1 (0.3%)	---
Hub Community	6 (1.9%)	3 (1.0%)	3 (1.0%)	1 (0.3%)	---
Other Place in Alaska	22 (7.1%)	7 (2.3%)	7 (2.3%)	5 (1.6%)	3 (1.0%)
Missing	2 (0.6%)	8 (2.6%)	112 (36.2%)	226 (73.1%)	181 (58.6%)

Instrumentation

Alaska breast cancer needs assessment survey (ABCNAS). In developing the ABCNAS, a literature search was conducted to locate breast cancer or general cancer needs assessment surveys previously developed. None of the identified surveys overlapped sufficiently with the goals of the project, which were to increase knowledge about breast cancer survivorship in Alaska and provide information about service needs or improvements. As a result, the creation of a new survey was deemed most appropriate, using previously developed surveys as a guide.

Survey development. Three surveys were determined to overlap to a sufficient degree with the goals of the CBHRS project and collectively covered the breadth of the

survivorship spectrum. Together, they addressed a range of domains that fully captured the multi-dimensional nature of the survivorship experience. Thus, all three existing survey were used to guide development of the Alaska Breast Cancer Needs Assessment Survey.

1. Living Beyond Breast Cancer - Advanced Breast Cancer Needs Assessment Survey (Mayer & Grober, 2006)
2. Cancer Survivors' Unmet Needs Measure (CaSUN) (Hodgkinson et al., 2007a)
3. LIVESTRONG Survey for Post-Treatment Cancer Survivors (Rechis-Oelker & Robinson, 2005)

Using these survey instruments, additional literature reviews, and anecdotal information collected from local providers and patients, broad assessment domains were identified for the creation of the ABCNAS. Under each domain, individual assessment items were generated or adapted from the three instruments named above and from informal interviews with informants until each domain was fully captured. Individual survey items were grouped into five overarching need domains in the initially constructed survey:

- Treatment and Services
- Physical Challenges
- Psychological Challenges
- Life Functioning
- Informal Support

Survey pilot testing and refinement. Eight breast cancer survivors were recruited from local breast cancer advocacy and non-profit groups to pilot the survey in either online or paper format. Pilot tests lasted from one to two hours and were conducted individually in a private office to encourage honest and open feedback about the relevance of the survey to each participant, especially in their role as breast cancer survivors. Queries regarding additions, changes, and deletions to content and format were made and documented throughout each pilot test. Feedback was compiled and the

survey was adapted and changed to reflect important themes that emerged in piloting. In addition of minor recommendations provided across domains, the majority of recommendations fell into three broad categories, as follows:

- create an easier and faster response format
- lower the reading level to accommodate a broad range of potential participants
- create additional questions related to communication with providers

After each concern was addressed, including a simple grid response format where possible, easier vocabulary, and addition of questions adapted from Mayer and Grober (2006) addressing communication with providers, two additional pilot tests were conducted to elicit further feedback about the revised survey before launching the needs assessment statewide. This additional pilot produced only minor additional suggestions and revisions.

Description of the final Alaska breast cancer needs assessment survey. The final survey included six sections, one each for Treatment and Services, Communication with Providers, Physical Wellbeing, Psychological Wellbeing, Daily Living, and Relevant Demographics and Disease History. Within each section, items assessed needs, experiences, satisfaction, and desire for additional information as relevant. A copy of the survey is provided in Appendix A. The survey could be administered online or hardcopy. The online survey was freely available; the paper version was mailed upon request to female breast cancer survivors living in Alaska. The survey was preceded by a set of screening questions to assure respondents met study characteristics (respondents had to be female, at least 18 years of age, and currently living in Alaska).

Treatment and services. In the Treatment and Services domain, participants were asked to rate their satisfaction regarding different types of treatment and services in the subcategories of diagnostic and screening tests, common breast cancer treatments, additional treatment and services, alternative and complementary treatments, formal psychological services, and organized support services. Satisfaction was measured using three response options (mostly satisfied, mostly dissatisfied, and did not receive these services). If individuals marked that they were mostly dissatisfied or did not receive

these types of services, they were asked to identify reasons for not receiving the service or being dissatisfied with the service provided from a list that included choices such as "*I had no need for it*", "*painful or side effects*", "*no insurance coverage*", or "*not available where I live*" (Appendix A shows the full listing).

Method of information delivery. To enhance understanding of preferred methods of delivering information to Alaskan breast cancer survivors about various treatments and services, participants were asked to select preferred methods of receiving information related to the five major treatment and services areas assessed. Options from which to choose were as follows:

- I do not want information
- Mailings or newsletters through the mail
- Electronic mailings or newsletters
- Consultation with a healthcare provider
- Website
- Books, brochures, magazines, handouts
- Video, telephone, or online educational talks
- Conferences, seminars, workshops or in-person educational talks
- Medical journals and articles for professionals
- Other methods _____

Provider communication. The Provider Communication domain identified a list of 11 provider types; participants were asked to rate how well each type of providers communicated with breast cancer survivors within the five communication domains listed below. Items were rated on a 4-point Likert-scale ranging from *strongly disagree* to *strongly agree*. Participants also had the option to select "*not applicable*" and "*did not have this type of provider.*"

- Provider was up-to-date on the best treatments
- Provider offered a variety of treatment options
- Provider communicated well with other providers
- Provider made appropriate referrals

- Provider listened and treated me with respect and caring

Physical wellbeing, psychological wellbeing, and daily living. The Physical Wellbeing, Psychological Wellbeing, and Daily Living domain asked participants to identify duration of symptoms and side effects related to physical wellbeing (22 symptoms), psychological wellbeing (23 symptoms), and activities related to daily living challenges (nine activities). For each symptom, respondents were asked to identify whether it had never been a problem, been a short-term problem, been a long-term problem that did or will go away, or been a long-term problem that might not go away.

Demographic and disease history. In addition to the previous six domains participants completed a Demographic and Disease History. These items queried participants about various demographic data, including educational level and employment; information related to the status of their breast cancer, such as stage of the disease when diagnosed; and geographic information, such as location of diagnosis and treatment and length of travel to and from treatment. An open-ended question followed the survey to give participants opportunity to express additional comments or thoughts. Table 10 provides an overview of the final Alaska Breast Cancer Needs Assessment Survey; Appendix A contains a complete copy of the instrument.

Table 10

Overview of the Alaska Breast Cancer Needs Assessment Survey

Survey Domains	*How Assessed*
Treatment and Services • Diagnostic and screening tests • Common treatments • Additional treatments and services • Alternative/ Complementary treatments and services • Formal psychological services • Organized support services	• Utilization • Satisfaction • Reasons for dissatisfaction • Reasons not received
Communication with Providers • healthcare providers types	• Utilization • Satisfaction with interaction for each provider type across five dimensions
Physical Wellbeing • physical symptoms	• Symptoms experienced • Duration
Psychological Wellbeing • psychological challenges	• Symptoms experienced • Duration
Daily Living • Employment • Financial issues • Health and life insurance • Household issues • Legal issues • End of life choices	• Problems experienced • Duration • Utilization of services for • Satisfaction • Reasons for dissatisfaction • Reasons not received
Demographic Information and Disease History	• Status of breast cancer • Stage at diagnosis • Primary location of diagnosis and treatment • Primary cultural heritage • Level of education • Employment status • Health insurance status • Household income

Method

CBHRS submitted all procedures and instruments to the University of Alaska Anchorage Institutional Review Board and received approval for the study (see Appendix B for a copy of the approval letter). With regard to survey procedures CBHRS posted the survey online using a link on their website, http://bhrs.uaa.alaska.edu/. The survey link was widely publicized to a variety of sources within the breast cancer community through a number of recruitment efforts. The survey was posted online December 5, 2008 and removed May 15, 2009, for a duration of approximately six months. Participants without

internet access or who preferred to complete a paper version had the option of requesting to have a copy of the survey mailed to them. Copies of the survey were returned in a prepaid envelope. Upon receipt, they were edited, keyed, and rekeyed using a specially-developed data entry program. Potential respondents were informed in detail about the survey and all procedures through an informed consent form. The informed consent document also explained that respondents' identity was protected and their confidentiality was guaranteed.

Prior to utilizing these archival data for Phase One for the current study, the research plan was submitted to and approved by the UAA Institutional Review Board (IRB). Data analyses began following this authorization. A copy of the IRB approval letter is included in Appendix B

Quantitative data analyses. The Statistical Package for the Social Sciences version 17.0 (SPSS for Windows), a comprehensive statistical software package, was used for all quantitative data analyses. Three sets of independent variables were created and utilized, namely, Survivorship Phase (acute, expanded, permanent), Age at Diagnosis (older survivors, younger survivors), and Access to Treatment (high access, low access) (see Table 11). Survivorship phase was defined by three phases: acute (length of time from diagnosis to completion of initial treatment), extended (one to three years post-diagnosis), and permanent (more than three years post-diagnosis). Survivorship phase was calculated subtracting self-reported month and year of diagnosis from month and year the survey was completed. Age at diagnosis was categorized as younger survivors (diagnosed prior to age 50 years old) and older survivors (diagnosed at or after age 50 years old). Age at diagnosis was calculated by the month and year the survey was taken compared to the month and year the participant was born. Lastly, access to treatment services was defined by having high access (Anchorage, Fairbanks) and low access (outside Alaska, Juneau, hub community, other place in Alaska) to primary treatment services.

Table 11

Frequencies of Independent Variables

Independent Variables	*N*	*%*
Age at Diagnosis (n = 292)		
Younger Survivors	141	45.6
Older Survivors	151	48.9
Missing	17	5.5
Survivorship Phase (n = 299)		
Acute	38	12.3
Extended	94	30.4
Permanent	167	54.0
Missing	10	3.2
Access to Primary Treatment Services (n = 301)		
High Access	260	84.1
Low Access	41	13.3
Missing	8	2.6

Using these three independent variables, the dataset was analyzed to address five primary research questions (see Table 11). Set One explored whether survivors received or did not receive certain cancer-related treatment and services. Set Two explored survivors' information needs across treatment and services domains. Set Two also assessed survivors' preferred method of information delivery regarding different types of breast cancer treatments and services obtained. Sets Three, Four, and Five assessed the severity of survivors' current physical wellbeing, psychological wellbeing, and daily living challenges. A further description of the independent and dependent variables, listed by five research questions analyses are provided below. Data analyses included several different statistical tests, including descriptive statistics, chi-square, ANOVA, and MANOVA. Data analysis procedures are outlined in Table 12.

Table 12

Quantitative Data Analysis Procedure

Research Question #1: Research Question #1: What cancer-related services are Alaska breast cancer survivors receiving and not receiving?		
Dependent Variables	*Independent Variables*	*Statistical Analyses*
Services not received: 1. Diagnostic & Screening Tests 2. Common Breast Cancer Treatments 3. Additional Treatment and Services 4. Alternative and Complementary Treatments 5. Formal Psychological Services 6. Organized Support Services 7. Daily Living	1. Access to treatment 2. Survivorship Phase 3. Age at diagnosis	1. Frequencies 2. Chi-square analysis test of association
Research Question #2: What are the identified information needs of breast cancer survivors related to cancer services in Alaska? Does need for information related to breast cancer services differ among groups of survivors?		
Dependent Variables	*Independent Variables*	*Statistical Analyses*
Need for information about: 1. Diagnostic & Screening Tests 2. Common Breast Cancer Treatments 3. Additional Treatment & Services 4. Alternative and Complementary Treatments 5. Formal Psychological Services 6. Organized Support Services 7. Physical Wellbeing 8. Psychological Wellbeing 9. Daily Living	1. Access to treatment 2. Survivorship Phase 3. Age at diagnosis	1. Rank order identified best way to provide information 2. Frequencies 3. Chi-square analysis test of association
Research Question #3: What are the primary physical symptoms that breast cancer survivors experience during the survivorship continuum?		
Dependent Variables	*Independent Variables*	*Statistical Analyses*
Physical Wellbeing Scales: 1. Pain/Fatigue 2. Hormonal Side Effects 3. Chemotherapy Side Effects 4. Radiation Therapy Side Effects	1. Access to treatment 2. Survivorship Phase 3. Age at diagnosis	1. Exploratory factor 2. Cronbach's alpha 3. Comparison of Means 4. MANOVA 5. ANOVA 6. Post hoc analyses
Research Question #4: What are the primary psychological concerns that breast cancer survivors experience during the survivorship continuum?		
Dependent Variables	*Independent Variables*	*Statistical Analyses*
Psychological Wellbeing Scales: 1. Feelings 2. Relationships 3. Meaning 4. Fear 5. Sex & Appearance	1. Access to treatment 2. Survivorship Phase 3. Age at diagnosis	1. Exploratory factor 2. Cronbach's alpha 3. Comparison of Means 4. MANOVA 5. ANOVA 6. Post hoc analyses

Continue Table 12

Research Question #5: What are the primary daily living challenges breast cancer survivors experience during the survivorship continuum?		
Dependent Variables	*Independent Variables*	*Statistical Analyses*
Daily Living Scales: 1. Economic/Financial Issues 2. Legal Issues	1. Access to treatment 2. Survivorship Phase 3. Age at diagnosis	1. Exploratory factor analysis 2. Cronbach's alpha 3. Comparison of Means 4. MANOVA 5. ANOVA 6. Post hoc analyses

Qualitative Research Phase (Phase Two)

Phase Two was implemented to contextualize quantitative findings and better understand healthcare providers' perceived barriers and challenges to meeting the needs of breast cancer survivors in Alaska. Qualitative interviews were conducted with healthcare providers, stratified by primary service categories (direct medical versus supportive care services). The participant selection plan sought to gain various perspectives across geographic location, medical specialty area, and level of expertise to ensure adequate representation of Alaska's diversity.

Participants

Interviews were conducted with 31 healthcare providers, including 25 women and six men, with a mean age of 52 years (SD = 11.0; ranging from 29 to 70 years). All healthcare providers, with the exception of one, self-identified as Caucasian. Due to the variety of interviewed healthcare providers and the small population of individuals who work with breast cancer survivors in Alaska, it is not possible to provide detail about professional identity and affiliation without revealing participants' identities. Thus, the sample is only described in terms of those who deliver direct medical services (n = 9 cancer specific providers; n = 8 general practitioners) and those who deliver supportive care services (n = 7 counseling support; n = 7 social and information support) (see Figure 2).

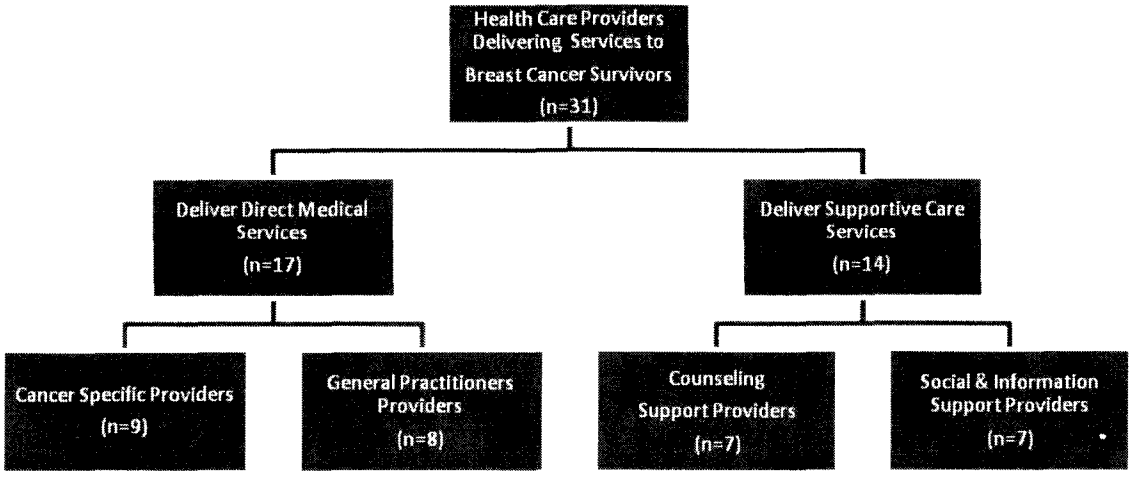

Figure 2. Key Informant Interviewee Stratified Sample

Healthcare providers reported an average of 23.6 years of professional experience (*SD* = 12.7; ranging from 3 to 47 years) with an average of 16.5 years of practice in Alaska (*SD* = 11.3; ranging from 1 to 29 years). Incidentally, of the participants, eight identified themselves as breast cancer survivors and nine identified themselves as support group facilitators. Primary residence was in a rural community for one individual; 28 interviewees lived in urban communities and two were itinerant workers in both urban and rural communities.

Instrumentation

A key informant interview protocol was developed based on review of Phase One quantitative findings, past research on key topics related to meeting needs of breast cancer survivors, and current areas of improvement healthcare providers can identify who work directly with breast cancer survivors. Consistent with the exploratory nature of Phase Two, the key informant interview protocol was semi-structured and contained 10 open-ended questions. Using a semi-structured protocol facilitates exploration of unanticipated issues and pursuit of rich examples while maintaining a core set of questions (Denzin & Lincoln, 1993). Special attention was given to gaining specific and in-depth information about healthcare providers' perception of extant barriers faced by breast cancer survivors in Alaska and ways to meet these needs systematically. A copy of the key informant protocol is provided in Appendix D.

Procedures

Prior to implementation, the qualitative project was reviewed and approved by the UAA IRB. Appendix H contains a copy of the letter of approval.

Participant selection. Healthcare providers were selected from existing healthcare networks within Alaska by utilizing a snowball sampling technique and random selection. These procedures were used with the goal of gaining various perspectives across geographic location, specialty area, and level of expertise that were representative of Alaska's vast diversity. Snowball sampling is recognized as especially useful in contacting difficult-to-reach populations, such as healthcare providers who have experience working with breast cancer survivors (Berg, 2009). For purposes of this study, snowball sampling began by directly contacting healthcare providers in the Anchorage area who were known for working with breast cancer survivors (i.e., medical and radiation oncologist, support group facilitators, and mental health providers specializing in oncology). Through those contacts, providers suggested other possible contacts across Alaska whom they perceived as having experience working with breast cancer survivors. In addition, liaisons for the American Cancer Society and for Alaska's Comprehensive Cancer Control were contacted and a list of names was obtained as potential viable contacts for the study.

To supplement the snowball selection process, direct healthcare providers (physicians and nurse practitioners) who were listed as specializing in oncology, hematology, or radiation oncology were randomly selected from the Alaska State Medical Association Directory. Utilizing these additional selection processes provided an opportunity to add participants to the pool of recruits with the goal of filling gaps in geographic and specialty representation. The majority of participants (90%) were recruited through snowball sampling efforts and approximately 10% were recruited through information obtained from the Alaska State Medical Association Directory.

Participant recruitment. Potential participants were contacted via telephone and email, and asked to participate in a 30-60 minute interview about the needs of breast cancer survivors in Alaska. Interviews were conducted in person or by telephone,

depending on the interviewee's place of residence. All interviews used the same procedures and were digitally recorded for transcription. Of 57 providers contacted, 31 (54.4%) agreed to participate. Three providers declined at the time of first contact, two providers stated they would be interested in participating, but never responded to follow-up contacts, one provider scheduled an interview and had to cancel indefinitely, and the remaining 22 healthcare providers did not respond to any contact attempts. The average number of email contacts per provider was 1.1, average number of telephone contacts was 1.1, and the average number of faxed information provided was 1.0.

Interview implementation. Once interviewees agreed to participate in the study, they were asked to read and sign an informed consent document and were given an opportunity to ask questions related to study purpose and procedures. If the interview took place via telephone, the informed consent form was faxed to the participant prior to the time of the interview and a signed consent form was returned to the researcher via fax or mail. Prior to starting the interview, the researcher reviewed the consent form with each participant to confirm her or his understanding and signature. After consent had been confirmed, the participant received a copy of the signed informed consent form. If the interview was held telephonically, the researcher mailed the participant a copy of the signed consent form, containing signatures of both the participant and the researcher. The 31 completed interviews were implemented in a one-on-one format by the researcher either in person ($n = 28$) or over the telephone ($n = 3$) and required an average of 48 minutes per interview (with a range of 30-60 minutes). The researcher began each formal interview by reminding participants about the audio-taping of the interview, followed by asking the questions outlined in the semi-structured interview protocol. When the interview was complete, participants were thanked and given a $50 gift certificate for Fred Meyers. If the interview took place by telephone, the researcher mailed the $50 gift certificate with the signed consent form. All interviewees were asked if they wanted to receive aggregated research results upon the study's completion; 22 of the 31 participants requested study results.

Qualitative Data Analyses

Digital audio recordings were transcribed in MS Word and imported into NVivo software (QSR International, 2008) for qualitative data coding based on grounded theory (Stake, 1995; Strauss & Corbin, 1998). Qualitative analytic procedures followed guidelines for assessing themes, domains, issues, and items as described below (Strauss & Corbin, 1998). Emphasis was placed on analyzing for themes and constructs to increase understanding of healthcare providers' perspectives of the needs of breast cancer survivors in Alaska and identify ways to systemically meet these needs.

Line-by-line open coding by two coders (including the researcher) of six transcripts was used to create a list of potential free nodes (concepts). Each free node was discussed by the two coders and examined for retention or deletion. Retained free nodes were then explicitly defined. During this initial stage, coders met regularly to review newly emerging free nodes and confirm that all phenomena were accounted for during the open coding process. Disagreements in coding were addressed by merging coded interviews prior to the coding meetings, identifying disagreements in the coding by comparing user coding stripes, and reviewing whether a code was applied appropriately (subsequently coding it to both projects) or applied inappropriately (subsequently un-coding it from both projects). New free nodes were created only if it was not possible to incorporate a theme into an existing free node definition. The coding process was iterative in nature (i.e., any changes to the codebook or process were applied to previously coded interviews). Upon completion of the open coding stage, a codebook containing detailed definitions of each node was developed to assist coders in maintaining reliability. Following this process, the first six interviews were recoded by both coders to establish interrater reliability. Based on these initial six interviews, it was established through the comparison of coding stripes that coders were coding in an almost identical manner across interviews and paragraphs. The remaining 16 interviews were double-coded individually; coding was compared following 10 transcripts and again after the remaining six transcripts to ensure maintenance of interrater reliability throughout the coding process.

Chapter 4 Quantitative Research Results

Analysis of the Needs of Female Breast Cancer Survivors in Alaska

Breast cancer treatments and services. As a component of the ABCNAS, breast cancer survivors responded to seven domains of the treatments and services they may have received. More specifically, women were asked about their utilization of cancer services related to diagnostic and screening tests, common breast cancer treatments, additional treatments and services, alternative and complementary treatments, formal psychological services, organized support services, and daily living challenges. Each domain was comprised of subcategories that closely related to the overall theme of the domain (see Table 13).

The majority of women received services related to *Diagnostic and Screening Tests*. Nearly all women received a breast exam (1.9% did not receive); and the fewest number of women (14.2%) received a PET scan. In terms of *Common Breast Cancer Treatments*, women were most likely to not receive hormone therapy (56.6%), followed closely by chemotherapy (46.9%), receiving a full/partial mastectomy (44.3%), and a lumpectomy and radiation therapy (36%). Women varied with regard to the *Additional Treatments and Services* they received. Women were least likely to receive services related to clinical trials (87.7%), reconstructive surgery (77.0%), and genetic testing (76.7%). In the category of *Alternative and Complementary Services*, women were least likely to receive services for relaxation, meditation, or imagery (75.4%), followed by supplements and herbs (72.8%), nutrition and diet (60.5%), and massage, exercise, and yoga (59.5%). The majority of women who completed the survey did not receive *Formal Psychological Services* in the forms of individual (74.4%), couples therapy (93.8%), or family (96.4%) counseling services. Women also did not receive counseling services for their spouse or partner (96.1%) or children (95.8%). With regard to *Organized Support Services*, the most commonly utilized services were support groups (40.8%); the majority of women did not receive services related to telephone hotline support (93.9%), on-line support (88.3%), spiritual support (77.1%), or one-on-one support (73.8%). Lastly,

related to *Daily Living Challenges,* 59.2% of women did not receive services for financial and economic issues and the majority (88.3%) did not receive legal services.

Table 13

Received Breast Cancer Treatments and Services

Diagnostic and Screening Tests	*N*	*% Received*	*N*	*% Not Received*
Breast Exam	303	98.1%	6	1.9%
Mammogram: Film	230	74.7%	78	25.3%
Mammogram: Digital	212	68.6%	97	31.4%
Breast Biopsy	217	70.5%	91	29.5%
Breast Ultrasound	283	91.9%	25	8.1%
PET	44	14.2%	265	85.8%
MRI	172	55.7%	137	44.3%
Common Breast Cancer Treatments				
Lumpectomy	197	64.0%	111	36.0%
Full/Partial Mastectomy	172	55.7%	137	44.3%
Chemotherapy	164	53.1%	145	46.9%
Hormone Therapy	134	43.4%	175	56.6%
Radiation Therapy	197	64.0%	111	36.0%
Additional Treatments and Services				
Breast Prosthesis	103	33.3%	206	66.7%
Reconstructive Surgery	71	23.0%	238	77.0%
Physical Therapy	85	27.5%	224	72.5%
Clinical Trials	38	12.3%	271	87.7%
Second Opinion	99	32.0%	210	68.0%
Genetic Testing	72	23.3%	237	76.7%
Alternative and Complementary Treatments				
Nutrition and Diet	122	39.5%	187	60.5%
Supplements and Herbs	84	27.2%	225	72.8%
Massage, Exercise, Yoga, etc.	125	40.5%	184	59.5%
Relaxation, Meditation, Imagery, etc.	76	24.6%	233	75.4%
Formal Psychological Services				
Individual Counseling	79	25.6%	230	74.4%
Family Counseling	11	3.6%	298	96.4%
Couples Counseling	19	6.2%	288	93.8%
Counseling for Spouse/Partner	12	3.9%	297	96.1%
Counseling for Child(ren)	13	4.2%	295	95.8%
Organized Support Services				
Support Groups	126	40.8%	183	59.2%
Online Support Groups	36	11.7%	273	88.3%
One-on-One Peer Support	81	26.2%	228	73.8%
Telephone Hotline Support	19	6.1%	290	93.9%
Spiritual Support	69	22.3%	240	77.7%
Daily Living Services				
Financial/Economic Services	126	40.8%	183	59.2%
Legal Services	36	11.7%	273	88.3%

Breast cancer services not received by survivorship phase. To determine whether there was a relationship between receipt of breast cancer services and survivorship phase, chi-square tests of independence were conducted for each of the seven treatment and services domains. For effect size, Cramer's V was reported for significant findings. The 2 x 3 comparisons were made based on item responses (received/not received) and survivorship phase (acute, extended, permanent).

Tables 14 through 16 provide an overview of the frequency with which breast cancer survivors identified services they did not receive related to *Alternative and Complementary Treatments*, *Formal Psychological Services*, and *Organized Support Services*, based on survivorship phase. Chi-square analyses within the *Organized Support Services* domain revealed a significant difference for online support groups, $\chi^2(2, N=299) = 8.83, p = .01$; and telephone hotline support, $\chi^2(2, N=299) = 6.54, p = .04$. Women in the permanent phase were less likely to receive services in the form of online support groups or telephone hotline support than those in the acute and extended phase. Effect sizes for these analyses were small (V = .17 and V = .15, respectively). Chi-square analyses for survivorship revealed no other significant differences within the three breast cancer treatment and services domains.

Table 14

Alternative and Complementary Treatments Not Received, by Survivorship Phase

	Survivorship Phase			
	Acute Phase	Extended Phase	Permanent Phase	Sig. Level
Nutrition & Diet (n =179)				
Number	19	52	108	.14
Percent not received	10.6%	29.1%	60.3%	
Supplements & Herbs (n = 217)				
Number	30	64	123	.40
Percent not received	13.8%	29.5%	56.7%	
Massage, Exercice, Yoga, etc. (n = 179)				
Number	21	52	103	.54
Percent not received	11.7%	29.1%	57.5%	
Relaxation, Meditation, Imagery, etc. (n = 223)				
Number	28	69	126	.93
Percent not received	12.6%	30.9%	56.5%	

Table 15

Formal Psychological Services Not Received, by Survivorship Phase

	Survivorship Phase			
	Acute Phase	Extended Phase	Permanent Phase	Sig. Level
Individual Counseling (n = 220)				
Number	30	64	126	.31
Percent not received	13.6%	29.1%	57.3%	
Family Counseling (n = 288)				
Number	30	64	126	.44
Percent not received	13.6%	29.1%	57.3%	
Couples Counseling (n = 278)				
Number	38	84	156	.18
Percent not received	13.7%	30.2%	56.1%	
Counseling for Spouse/Partner (n = 287)				
Number	38	88	161	.22
Percent not received	13.2%	30.7%	56.1%	
Counseling for Child(ren) (n = 285)				
Number	36	89	160	.96
Percent not received	12.6%	31.2%	56.1%	

Table 16

Organized Support Services Not Received, by Survivorship Phase

	Survivorship Phase			
	Acute Phase	Extended Phase	Permanent Phase	Sig. Level
Support Groups (n = 176)				
Number	19	62	95	.18
Percent not received	10.8%	35.2%	54.0%	
Online Support Groups (n = 263)				
Number	30	78	155	.01*
Percent not received	11.4%	29.7%	58.9%	
One-on-One Peer Support (n = 219)				
Number	26	66	127	.46
Percent not received	11.9%	30.1%	58.0%	
Telephone Hotline Support (n = 280)				
Number	32	89	159	.04*
Percent not received	11.4%	31.8%	56.8%	
Spiritual Support (n = 231)				
Number	30	74	127	.85
Percent not received	13.0%	32.0%	55.0%	

*p < .05 significance level

Breast cancer services not received by age at diagnosis. To determine whether there was a relationship between breast cancer services not received and age at diagnosis, chi-square test of independence was conducted for each of the three treatment and services domains for alternative and complementary services, formal psychological services, and organized support services. Fisher's Exact Test was used instead of Pearson Chi Square when there were fewer than five participants in at least one cell. For the current analysis, effect size, Cramer's V and odds ratio was reported for significant findings.

Tables 17 through 19 provide an overview of the frequency with which breast cancer survivors identified not receiving breast cancer treatment and services based on their age at diagnosis. A series of 2 x 2 comparisons were calculated based on item responses (received/not received) and age at diagnosis (younger survivor/older survivor). The chi-square analyses within the *Alternative and Complementary Treatment* domain revealed a significant difference for Massage, Exercise, and Yoga, $\chi^2(1, N=292) = 8.84$, $p = .003$. Odds ratio highlighted older survivors were 14.16 times more likely not to receive services related to massage, exercise, and yoga. Significant differences within the *Formal Psychological Services* domain were revealed for Counseling for Children, ($p = .001$). Odds ratio indicated older survivors were 2.04 times more likely not to receive services related to counseling for children than younger survivors. In general, older survivors reported receiving fewer services than younger survivors across most categories, but in many cases the differences were not significant. Effect sizes for these analyses were small (V = .17 and V = .19, respectively). Chi-square analyses for age revealed no other significant differences on other breast cancer treatment and services domains.

Table 17

Alternative and Complementary Treatments Not Received, by Age at Diagnosis

	Age at Diagnosis		
	Younger Survivors	Older Survivors	Sig. Level
Nutrition & Diet (n = 172)			.33
Number	79	93	
Percent not received	45.9%	54.1%	
Supplements & Herbs (n = 208)			.71
Number	99	109	
Percent not received	47.6%	52.4%	
Massage, Exercice, Yoga, etc. (n = 169)			.00**
Number	69	100	
Percent not received	40.8%	59.2%	
Relaxation, Meditation, Imagery, etc. (n = 216)			.09
Number	98	118	
Percent not received	45.4%	54.6%	

**p < .01 significance level

Table 18

Formal Psychological Services Not Received, by Age at Diagnosis

	Age at Diagnosis		
	Younger Survivors	Older Survivors	Sig. Level
Individual Counseling (n = 213)			.63
Number	101	112	
Percent not received	47.4%	52.6%	
Family Counseling (n = 281)			.30
Number	134	147	
Percent not received	47.7%	52.3%	
Couples Counseling (n = 272)			.41
Number	133	139	
Percent not received	48.9%	51.1%	
Counseling for Spouse/Partner (n = 280)			.90
Number	135	145	
Percent not received	48.2%	51.8%	
Counseling for Child(ren) (n = 278)			.00[a]**
Number	128	150	
Percent not received	46.0%	54.0%	

[a] Fisher's Exact Test was used instead of Pearson Chi Square due to having fewer than 5 in one cell

**P < .01 significance level

Table 19

Organized Support Services Not Received, by Age at Diagnosis

	Age at Diagnosis		
	Younger Survivors	Older Survivors	Sig. Level
Support Groups (n = 169)			.07
Number	67	56	
Percent not received	79.1%	87.5%	
Online Support Groups (n = 257)			.14
Number	21	14	
Percent not received	85.7%	78.6%	
One-on-One Peer Support (n = 214)			.33
Number	34	44	
Percent not received	97.1%	93.2%	
Telephone Hotline Support (n = 273)			.58
Number	8	11	
Percent not received	75.0%	81.8%	
Spiritual Support (n = 66)			.42
Number	29	37	
Percent not received	100.0%	94.6%	

Breast cancer services not received by access to primary treatment services. To determine whether there was a relationship between breast cancer services received and access to primary treatment services, chi-square tests of independence were conducted for each of the seven treatment and services domains. Tables 20 through 22 provide an overview of the frequency with which breast cancer survivors did not receive treatment and services based on their access to primary treatment services. A series of 2 x 2 comparisons were made based on item responses (received/not received) and access to primary treatment services (high access/low access). Chi-square analyses revealed no significant differences on the three breast cancer treatment and services domains.

Table 20

Alternative and Complementary Treatments Not Received, by Access to Treatment Services

	Access To Primary Treatment Services		
	High Access	Low Access	Sig. Level
Nutrition & Diet (n = 182)			.54
Number	23	159	
Percent not received	12.6%	87.4%	
Supplements & Herbs (n = 219)			.95
Number	30	189	
Percent not received	13.7%	86.3%	
Massage, Exercice, Yoga, etc. (n = 179)			.58
Number	26	153	
Percent not received	14.5%	85.5%	
Relaxation, Meditation, Imagery, etc. (n = 226)			.14
Number	27	199	
Percent not received	11.9%	88.1%	

Table 21

Formal Psychological Services Not Received, by Access to Treatment Services

	Access To Primary Treatment Services		
	High Access	Low Access	Sig. Level
Individual Counseling (n = 223)			.81
Number	31	192	
Percent not received	13.9%	86.1%	
Family Counseling (n = 290)			.65[a]
Number	40	250	
Percent not received	13.8%	86.2%	
Couples Counseling (n = 280)			.79[a]
Number	38	242	
Percent not received	13.6%	86.4%	
Counseling for Spouse/Partner (n = 289)			.16[a]
Number	41	248	
Percent not received	14.2%	85.8%	
Counseling for Child(ren) (n = 287)			.85[a]
Number	39	248	
Percent not received	13.6%	86.4%	

[a] Fisher's Exact Test was used instead of Pearson Chi Square due to having fewer than 5 in one cell

Table 22

Organized Support Services Not Received, by Access to Treatment Services

	Access To Primary Treatment Services		
	High Access	Low Access	Sig. Level
Support Groups (n = 177)			
Number	20	157	.16
Percent not received	11.3%	88.7%	
Online Support Groups (n = 265)			
Number	36	229	.96
Percent not received	13.6%	86.4%	
One-on-One Peer Support (n = 222)			
Number	31	191	.77
Percent not received	14.0%	86.0%	
Telephone Hotline Support (n = 282)			
Number	40	242	.27[a]
Percent not received	14.2%	85.8%	
Spiritual Support (n = 235)			
Number	32	203	1.00
Percent not received	13.6%	86.4%	

[a] Fisher's Exact Test was used instead of Pearson Chi Square due to having fewer than 5 in one cell

Analysis of Information about Breast Cancer Treatment and Services

Interest in additional information about breast cancer treatments and services domains. To assess the venue in which breast cancer survivors prefer to obtain additional information about treatment and services, frequency and percent of preferred method of information delivery were obtained (see Table 23). Interestingly, the preferred method of obtaining information on six of the seven domains was to consult with their healthcare providers. For the seventh domain, information about *Daily Living Services*, women preferred to obtain additional information through electronic mailings or newsletters.

Table 23

Interest in Additional Information about Breast Cancer Treatments and Services Domains

	Diag. & Screening Services	Common Treatments	Additional Treatments & Services	Alternative/ Complem. Treatments	Formal Psych. Services	Organized Support Services	Physical Wellbeing	Psych. Wellbeing	Daily Living
I do not require additional information	92 (29.8%)	97 (31.4%)	75 (24.3%)	64 (20.7%)	89 (28.8%)	84 (27.2%)	61 (19.7%)	74 (23.9%)	106 (34.3%)
Mailings or newsletters through the mail	31 (10.0%)	20 (6.5%)	31 (10.0%)	35 (11.3%)	34 (11.0%)	44 (14.2%)	46 (14.9%)	42 (13.6%)	40 (12.9%)
Electronic mailing or newsletters	40 (12.9%)	39 (12.6%)	42 (13.6%)	50 (16.2%)	38 (12.3%)	44 (14.2%)	57 (18.4%)	51 (16.5%)	46* (14.9%)
Consultation with a healthcare provider	75* (24.3%)	77* (24.9%)	86* (27.8%)	76* (24.6%)	80* (25.9%)	62* (20.1%)	64* (20.7%)	53* (17.2%)	23 (7.4%)
Website	24 (7.8%)	27 (8.7%)	21 (6.8%)	25 (8.1%)	15 (4.9%)	23 (7.4%)	33 (10.7%)	28 (9.1%)	26 (8.4%)
Books, brochures, magazines, handouts	12 (3.9%)	10 (3.2%)	10 (3.2%)	16 (5.2%)	9 (2.9%)	7 (2.3%)	17 (5.5%)	18 (5.8%)	14 (4.5%)
Video, telephone, or online education talks	2 (0.6%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (0.3%)	1 (0.3%)	0 (0.0%)	1 (0.3%)	14 (4.5%)
Conferences, seminars, workshop or in-person educational talk	19 (6.1%)	22 (7.1%)	22 (7.1%)	23 (7.4%)	22 (7.1%)	18 (5.8%)	17 (5.5%)	23 (7.4%)	24 (7.8%)
Medical journals & articles for professionals	3 (1.0%)	5 (1.6%)	2 (0.6%)	4 (1.3%)	3 (1.0%)	2 (0.6%)	4 (1.3%)	3 (1.0%)	2 (0.6%)
Other	2 (0.6%)	8 (2.6%)	8 (2.6%)	5 (1.6%)	6 (1.9%)	8 (2.6%)	5 (1.6%)	8 (2.6%)	7 (2.3%)
Missing	9 (2.9%)	4 (1.3%)	12 (3.9%)	11 (3.6%)	12 (3.9%)	16 (5.2%)	5 (1.6%)	8 (2.6%)	21 (6.8%)

*Preferred method of additional information delivery

Additional information by survivorship phase, age at diagnosis, and access to primary treatment. To determine whether there was a relationship between Survivorship Phase, Age at Diagnosis, and Access to Primary Treatment and interest in obtaining additional information, chi-square tests of independence were conducted for each of the seven Treatment and Services domains. For effect size, Cramer's V and odds ratios were reported for all significant findings in Set Two

Table 24 provides an overview of the frequency with which breast cancer survivors identified interest in obtaining additional information about treatment and services based on their survivorship phase. The 2 x 3 comparisons were based on need for information (no need/need) and survivorship phase (acute, extended, permanent). The chi-square analysis revealed no other significant differences on the nine domains.

Table 24

Percentage of Women Expressing Need for Additional Information about Treatments and Services, by Survivorship Phase

Topic	Survivorship Phase			
	Acute Phase (n = 38)	Extended Phase (n = 94)	Permanent Phase (n = 167)	Sig. Level
Diagnostic and Screening Services (n = 197)	24 (63.2%)	61 (64.9%)	116 (69.5%)	.64
Common Breast Cancer Treatments (n = 199)	25 (65.8%)	64 (68.1%)	112 (67.1%)	.97
Additional Treatments & Services (n = 214)	27 (71.1%)	73 (77.7%)	116 (69.5%)	.36
Alternative & Complementary Treatments (n = 223)	30 (78.9%)	72 (76.6%)	124 (74.3%)	.80
Formal Psychological Services (n = 197)	29 (76.3%)	60 (63.8%)	111 (66.5%)	.38
Organized Support Services (n = 198)	29 (76.3%)	63 (67.0%)	109 (65.3%)	.42
Physical Wellbeing (n = 230)	30 (78.9%)	78 (83.0%)	127 (76.0%)	.42
Psychological Wellbeing (n = 197)	28 (73.7%)	75 (79.8%)	116 (69.5%)	.19
Daily Living (n = 214)	23 (60.5%)	64 (68.1%)	88 (52.7%)	.05

Table 25 displays the frequency with which breast cancer survivors identified interest in obtaining addition information about treatment and services based on their age at diagnosis. As shown in the table, older survivors were more interested in obtaining additional information across all treatment and service domains as compared to younger survivors. The 2 x 2 comparisons were based on need for information (no need/need) and age at diagnosis (younger survivors/older survivors). Findings revealed that older breast cancer survivors were significantly more interested in obtaining information about *Common Breast Cancer Treatments* than their younger counterparts, $\chi^2(1, N=292) = 6.44$, $p = .01$. Odds ratio indicated older survivors were 1.90 times more likely to want additional information about common breast cancer treatment than younger survivors. Effect size for this analyses was small (V =.15). The chi-square analysis revealed no other significant differences on the other eight domains.

Table 25

Percentage of Women Expressing Need for Additional Information about Treatments and Services, by Age at Diagnosis

Topic	Age at Diagnosis		
	Younger Survivors (n = 141)	Older Survivors (n = 151)	Sig. Level
Diagnostic & Screening Services (n = 197)	89 (63.1%)	108 (71.5%)	.13
Common Breast Cancer Treatments (n = 199)	86 (61.0%)	113 (74.8%)	.01**
Additional Treatments & Services (n = 214)	97 (68.8%)	117 (77.5%)	.09
Alternative & Complementary Treatments (n = 223)	105 (74.5%)	118 (78.1%)	.46
Formal Psychological Services (n = 197)	90 (63.8%)	107 (70.9%)	.20
Organized Support Services (n = 198)	89 (63.1%)	109 (72.2%)	.10
Physical Wellbeing (n = 230)	105 (74.5%)	125 (82.8%)	.08
Psychological Wellbeing (n = 214)	100 (70.9%)	114 (75.5%)	.38
Daily Living (n = 172)	76 (53.9%)	96 (63.6%)	.09

**Significant at p < .01

Interest in obtaining additional information about breast cancer treatment and services based on survivors' access to primary treatment services is illustrated in Table 26. The 2 x 2 comparisons were based on need for information (no need/ need) and access to primary treatment (high access/low access). The chi-square analysis revealed no significant differences on the other nine domains.

Table 26

Percentage of Women Expressing Need for Additional Information about Treatments and Services, by Access to Treatment

Topic	Access To Primary Treatment		
	High Access (n = 260)	Low Access (n = 41)	Sig. Level
Diagnostic & Screening Services (n = 204)	176 (67.7%)	28 (68.3%)	.94
Common Breast Cancer Treatments (n = 205)	179 (68.8%)	26 (63.4%)	.49
Additional Treatments & Services (n = 219)	190 (73.1%)	29 (70.7%)	.75
Alternative & Complementary Treatments (n = 230)	197 (75.8%)	33 (80.5%)	.51
Formal Psychological Services (n = 204)	179 (68.8%)	25 (61.0%)	.32
Organized Support Services (n = 205)	177 (68.1%)	28 (68.3%)	.98
Physical Wellbeing (n = 237)	209 (80.4%)	28 (68.3%)	.08
Psychological Wellbeing (n = 293)	194 (74.6%)	28 (68.3%)	.39
Daily Living (n = 178)	155 (59.6%)	23 (56.1%)	.67

*Significant at $p < .05$ level

Analysis of Physical Wellbeing, Psychological Wellbeing, and Daily Living Challenges by Survivorship Phase, Age at Diagnosis, and Access to Treatment

The next three sets of analyses assessed the severity of survivors' current physical wellbeing, psychological wellbeing, and daily living challenges. For these analyses, subscales were identified through conducting exploratory factor analysis. More specifically, separate principal component analysis was conducted to identify the underlying factors for Physical Wellbeing, Psychological Wellbeing and Daily Living Challenges Scales of the ABCNAS. When conducting these factor analyses, a .40 criterion was set for inclusion of items; items that did not meet the .40 criteria were excluded from the grouped factors. For these analyses, participants were only included if they answered at least one-third of the items. Subsequent to identifying the underlying factors and developing subscales, preliminary analysis included multivariate analysis of variance (MANOVA). These MANOVAs included the three independent variables (survivorship phase, age, access to services) and the subscales as dependent variables. Follow-up analyses included running individual analysis of variance (ANOVAs) for each independent variable if the MANOVA including the subscales was significant. Post hoc analyses for survivorship phase, using Duncan's procedure, were conducted for all significant findings.

Analysis of Physical Wellbeing Items

Summary of physical wellbeing symptoms. Women were asked to identify the severity of 22 different physical symptoms that they may have experienced during their breast cancer treatment and following treatment completion. Table 27 provides a comprehensive overview of all 22 symptoms and how women rated each symptom related to severity.

Table 27

Duration of Physical Wellbeing Symptoms

		Never been a problem		Short-term problem		Long-term problem that did or will go away		Long-term problem that might not go away	
22 Physical Symptoms	*Total*	*N*	*%*	*N*	*%*	*N*	*%*	*N*	*%*
Difficulty walking or climbing stairs	300	181	60.3%	75	25.0%	14	4.7%	30	10.0%
Fatigue or tiredness	302	36	11.9%	146	48.3%	79	26.2%	41	13.6%
Breathing difficulties	296	207	69.9%	59	19.9%	17	5.7%	13	4.4%
Night sweats	299	99	33.1%	66	22.1%	67	22.4%	67	22.4%
Appetite loss	301	171	56.8%	111	36.9%	17	5.6%	2	0.7%
Nausea	301	159	52.8%	126	41.9%	13	4.3%	3	1.0%
Pain	301	77	25.6%	134	44.5%	40	13.3%	50	16.6%
Joint pain or muscle aches	300	98	32.7%	69	23.0%	49	16.3%	84	28.0%
Memory loss	299	135	45.2%	65	21.7%	37	12.4%	62	20.7%
Concentration difficulties	301	120	39.9%	85	28.2%	46	15.3%	50	16.6%
Sleep difficulties	299	79	26.4%	85	28.4%	58	19.4%	77	25.8%
Hair loss	301	127	42.2%	129	42.9%	32	10.6%	13	4.3%
Hot flashes	300	74	24.7%	78	26.0%	67	22.3%	81	27.0%
Fertility	292	242	82.9%	9	3.1%	10	3.4%	31	10.6%
Vaginal dryness or painful intercourse	291	136	46.7%	26	8.9%	31	10.7%	98	33.7%
Abnormal uterine bleeding	291	250	85.9%	18	6.2%	17	5.8%	6	2.1%
Lymphedema	295	184	62.4%	34	11.5%	21	7.1%	56	19.0%
Neuropathy	298	146	49.0%	49	16.4%	28	9.4%	75	25.2%
Weight gain or loss	301	107	35.5%	78	25.9%	63	20.9%	53	17.6%
Radiation burns	295	167	56.6%	102	34.6%	16	5.4%	10	3.4%
Loss of bone density	294	175	59.5%	19	6.5%	28	9.5%	72	24.5%
Mouth scores	296	205	69.3%	79	26.7%	7	2.4%	5	1.7%

Table 28 showcases the five most common physical symptoms and the five most common long-term problems identified by women. Participants identified that tiredness and fatigue (89.1%) was the most common physical problem followed by hot flashes (75.3%), pain (74.4%), sleep difficulties (73.6%), and joint/muscle aches (67.3%). Women identified the following physical symptoms they believe to be a long-term problem: hot flashes (49.3%), sleep difficulties (45.2%), night sweats (44.8%), joint pain or muscle aches and vaginal dryness or painful intercourse (44.3%) and fatigue and tiredness (39.7%).

Table 28

Most Common Physical Problems and Long-Term Problems

Five Most Common Physical Problems			*Five Most Common Long-term Physical Problems*		
	N	*%*		*N*	*%*
Tiredness & fatigue	266	89.1%	Hot flashes	148	49.3%
Hot flashes	226	75.3%	Sleep difficulties	135	45.2%
Pain	224	74.4%	Night sweats	134	44.8%
			Joint Pain or muscle aches	133	44.3%
Sleep difficulties	220	73.6%	Vaginal dryness or painful intercourse	129	
Joint/muscle aches	202	67.3%	Fatigue or tiredness	120	39.7%

Factor analysis of physical wellbeing items. The dimensionality of the 22 items that comprise the Physical Wellbeing domain of the ABCNAS was analyzed using principal component analysis with varimax (orthogonal) rotation. The rotated solutions, as shown in Table 29, yielded four interpretable factors, Pain/Fatigue, Hormonal Side Effects, Chemotherapy Side Effects, and Radiation and Surgery Side Effects. Of the 22 items, one item (Have mouth sores been a problem?) failed to meet the minimum criteria of having a primary factor loading criteria of .40 or above. The Pain/Fatigue factor accounted for 17.2% of the item variance, Hormonal Side Effects accounted for 13.4%, Chemotherapy Side Effects 11.4% and Radiation and Surgery Side Effects 6.9%. Only one item loaded on more than one factor. Internal consistency for each of the scales was determined using Cronbach's alpha, as shown in Table 30. Alphas coefficients for all four scales were adequate, with a coefficient of .82 for Pain/Fatigue, .74 for Hormonal

Side Effects, .72 for Chemotherapy Side Effects, and .42 for Radiation and Surgery Side Effects.

Table 29

Exploratory Factor Analysis of Physical Wellbeing Items

Rotated Component Matrix[a]					
	Components				Communalities
	1	2	3	4	
Has breathing difficulty been a problem?	.70				.53
Has walking or climbing stairs been a problem?	.67				.49
Has pain been a problem?	.62				.45
Has fatigue or tiredness been a problem?	.60				.53
Has joint pain or muscle aches been a problem?	.60				.52
Has neuropathy been a problem?	.53				.37
Has weight gain or loss been a problem?	.50				.37
Has appetite loss been a problem?	.45				.33
Have night sweats been a problem?		.84			.77
Have hot flashes been a problem?		.83			.73
Have sleep difficulties been a problem?	.43	.59			.56
Has vaginal dryness or painful intercourse been a problem?		.55			.40
Has loss of bone density been a problem?		.41			.26
Has hair loss been a problem?			.72		.55
Has memory loss been a problem?			.68		.73
Has concentration difficulties been a problem?			.65		.67
Has nausea been a problem?			.55		.45
Has fertility been a problem?			.43		.43
Have mouth sores been a problem?					.31
Have radiation burns been a problem?				.66	.51
Has abnormal uterine bleeding been a problem?				.59	.41
Has lymphedema been a problem?				.53	.40
Extraction Method: Principal Component Analysis. Rotation Method: Varimax with Kaiser Normalization.					
a. Rotation converged in 6 iterations.					

Table 30

Means, Standard Deviations, and Coefficient Alpha for Physical Wellbeing Items (N=309)

Variables	# of items	*N*	*M*	*SD*	Min	Max	Coefficient Alpha
Pain/Fatigue	9	268	2.04	.64	1.44	2.47	.82
Hormonal Side Effects	5	269	2.31	.85	1.98	2.50	.74
Chemotherapy Side Effects	5	278	1.76	.66	1.41	2.08	.72
Radiation Side Effects	3	284	1.53	.60	1.23	1.81	.42

Preliminary analysis of physical wellbeing. A 2 (Access to Treatment) x 3 (Survivorship Phase) x 2 (Age at Diagnosis) multivariate analyses of variance (MANOVA) was conducted with dependent variables being the four Physical Wellbeing subscales (Pain/Fatigue, Hormonal Side Effects, Chemotherapy Side Effects, and Radiation Side Effects). No two-way or three-way interactions were found to be significant. However, when conducting the MANOVA with all three independent variables, the total number of participants was reduced to approximately 40 participants due to missing data. Consequently, separate analyses were conducted for each of the three independent variables.

Primary analyses of physical wellbeing items. Table 40 displays the means and standard deviations of the Physical Wellbeing subscales by the three independent variables. Separate one-way MANOVAs were conducted for each of the three independent variables using the four subscales (Pain/Fatigue, Hormonal Side Effects, Chemotherapy Side Effects, and Radiation Side Effects) as dependent variables. Significant results were found for Age at Diagnosis, Wilks' Lambda = .94, $F(4, 278) = 4.51$, $p = .002$, and Survivorship Phase, Wilks' Lambda = .92, $F(8, 568) = 2.85$, $p = .004$. The effect size for these findings were small, Age at Diagnosis, $\eta^2 = .06$ and Survivorship Phase, $\eta^2 = .04$. No significant results were found for Access to Primary Treatment Services, Wilks' Lambda = 1.00, $F(4,288) = .30$, *ns*.

As a follow-up to the significant MANOVAs, analyses of variance (ANOVAs) were conducted for each of the four subscales. Bonferroni correction was applied to control for familywise error rate. Univariate results revealed significant findings for two

of the five subscales for the independent variable of Age at Diagnosis and one subscale for Survivorship Phase. For Age at Diagnosis, results did not remain significant with the adjusted alpha level ($p < .0125$). Based on Survivorship Phase, results showed significant differences for the dependent variable Pain/Fatigue, $F(2,295) = 5.12$, $p = .01$. Post hoc analysis using Duncan's procedure revealed women in the extended phase ($M = 2.24$, $SD = .67$) experienced more symptoms related to pain and fatigue when compared to survivors in the acute phase ($M = 2.00$, $SD = .61$) and the permanent phase ($M = 1.97$, $SD = .65$), who did not differ significantly from one another (see Table 31). No significant differences were found pertaining to the subscales of Hormonal Side Effects, Chemotherapy Side Effects, and Radiation and Surgery Side Effects.

Analysis of Psychological Wellbeing Items

Summary of psychological wellbeing symptoms. Women were asked to identify the severity of 23 different psychological symptoms that they may have experienced during their breast cancer treatment and following treatment completion. Table 32 provides a comprehensive overview of all 23 symptoms and how women rated each symptom related to severity.

Table 33 provides an overview of the five most common psychological symptoms and the five most common long-term problems identified by women. Participants identified that fear of cancer returning (86.9%) was the most common psychological problem, followed by being anxious (83.3%), stressed (82.8%), feeling overwhelmed (82.8%), and having fear of cancer spreading (79.9%). Women identified the following psychological symptoms, to be long-term problems: fear of cancer returning (69.8%), fear of cancer spreading (56.9%), worrying about the future (44.0%), worrying about sexuality (30.2%), and being stressed (32.7%).

Table 31

Means, Standard Deviations, and Frequencies of Psychological Wellbeing Items

Physical Wellbeing Subscales		*Access to Primary Treatment*			*Survivorship Phase*				*Age at Diagnosis*		
		High Access	*Low Access*	*Total*	*Acute Phase*	*Extended Phase*	*Permanent Phase*	*Total*	*Younger Survivors*	*Older Survivors*	*Total*
Pain/Fatigue (9 items)	*N*	262	38	300	38	94	166	298	141	150	291
	M	2.04	2.11	2.05	2.00	2.24	1.97	2.06	2.03	2.06	2.05
	SD	.65	.73	.66	.61	.67	.65	.66	.58	.74	.67
Hormonal (5 items)	*N*	259	37	296	37	93	164	294	141	146	287
	M	2.33	2.27	2.33	2.25	2.33	2.38	2.35	2.35	2.31	2.33
	SD	.85	.89	.86	.81	.82	.88	.85	.85	.87	.86
Chemotherapy side effects (5 items)	*N*	259	38	297	37	94	163	294	140	147	287
	M	1.78	1.86	1.79	1.71	1.80	1.81	1.79	1.90	1.71	1.80
	SD	.67	.74	.67	.56	.66	.69	.66	.66	.67	.67
Radiation Side Effects (3 items)	*N*	257	38	295	38	93	162	293	140	146	286
	M	1.70	1.63	1.69	1.62	1.65	1.75	1.70	1.79	1.59	1.69
	SD	.71	.72	.71	.65	.71	.73	.71	.77	.65	.72

Table 32

Duration of Psychological Wellbeing Symptoms

		Never been a problem		Short-term problem		Long-term problem that did or will go away		Long-term problem that might not go away	
23 Psychological Symptoms	*Total*	*N*	*%*	*N*	*%*	*N*	*%*	*N*	*%*
Hopelessness	298	180	60.4%	86	28.9%	23	7.7%	9	3.0%
Feeling overwhelmed	305	61	20.0%	170	55.7%	56	18.4%	18	5.9%
Depressed	305	99	32.5%	125	41.0%	50	16.4%	31	10.2%
Stressed	303	52	17.2%	152	50.2%	69	22.8%	30	9.9%
Anxious	305	51	16.7%	166	54.4%	55	18.0%	33	10.8%
Angry	302	146	48.3%	112	37.1%	33	10.9%	11	3.6%
Fear of cancer returning	305	40	13.1%	52	17.0%	53	17.4%	160	52.5%
Fear of cancer spreading	304	61	20.1%	70	23.0%	45	14.8%	128	42.1%
Fear of pain	300	164	54.7%	82	27.3%	26	8.7%	28	9.3%
Worries about appearance	305	121	39.7%	111	36.4%	33	10.8%	40	13.1%
Worries about sexuality	305	138	45.2%	75	24.6%	41	13.4%	51	16.7%
Isolation and loneliness	300	159	53.0%	82	27.3%	31	10.3%	28	9.3%
Worries about the future	302	86	28.5%	83	27.5%	46	15.2%	87	28.8%
Fear of death	300	144	48.0%	82	27.3%	27	9.0%	47	15.7%
Thoughts of being useless	302	199	65.9%	68	22.5%	15	5.0%	20	6.6%
Guilt or shame	301	247	82.1%	39	13.0%	8	2.7%	7	2.3%
Loss of control	302	151	50.0%	87	28.8%	36	11.9%	28	9.3%
Spiritual doubt	303	245	80.9%	39	12.9%	6	2.0%	13	4.3%
Spouse/partner troubled by my diagnosis	299	143	47.8%	87	29.1%	34	11.4%	35	11.7%
Child(ren) troubled by my diagnosis	296	134	45.3%	106	35.8%	32	10.8%	24	8.1%
Our family members troubled by my diagnosis	301	112	37.2%	128	42.5%	30	10.0%	31	10.3%
Stress in my relationship with spouse/partner because of my diagnosis	299	196	65.6%	61	20.4%	19	6.4%	23	7.7%
Stress in relationship with my child(ren) because of my diagnosis	296	222	75.0%	52	17.6%	14	4.7%	8	2.7%

Table 33

Most Common Psychological Problems and Long-Term Problems

Five Most Common Psychological Problems			Five Most Common Long-Term Psychological Problems		
	N	%		*N*	%
Fear of cancer returning	265	86.9%	Fear of cancer returning	213	69.8%
Being anxious	254	83.3%	Fear of cancer spreading	173	56.9%
Being stressed	251	82.8%	Worries about the future	133	44.0%
Feeling overwhelmed	244	80.0%	Worries about sexuality	92	30.2%
Fear of cancer spreading	243	79.9%	Being Stressed	99	32.7%

Factor analysis of psychological wellbeing items. The 23 items assessing psychological wellbeing were analyzed using principal component analysis with varimax (orthogonal) rotation (see Table 34). Results yielded the following five interpretable factors: Feelings, Relationships, Fear, Meaning, and Sex and Appearance. Of the 23 items, one item (Has fear of pain been a problem?) failed to meet the minimum criteria of having a primary factor loading of .40 or above. The Feelings factor accounted for 20.0% of the item variance, Relationships for 11.6%, Fear for 11.0%, Meaning for 10%, and Sex and Appearance for 8.8%. Two of the 23 items loaded on two separate factors. Internal consistency for each of the scales was examined using Cronbach's alpha, as shown in Table 35. All alpha coefficients were adequate with a coefficient of .89 for Feelings, .78 for Relationships, .82 for Fear, .65 for Meaning, and .70 for Sex & Appearance.

Table 34

Exploratory Factor Analysis of Psychological Wellbeing Items

Rotated Component Matrix[a]						
	Components					Communalities
	1	2	3	4	5	
Has feeling depressed been a problem?	.81					.69
Has feeling overwhelmed been a problem?	.80					.70
Has stress been a problem?	.80					.72
Has being anxious been a problem?	.77					.67
Has hopelessness been a problem?	.66					.50
Has loss of control been a problem?	.60					.50
Has isolation/loneliness been a problem?	.58					.56
Has anger been a problem?	.47					.48
Has fear of pain been a problem?						.34
Have other family members troubled by diagnosis been a problem?		.81				.71
Have children troubled by diagnosis been a problem?		.79				.67
Has spouse/partner troubled by diagnosis been a problem?		.69				.57
Has stress in your relationship with children been a problem?		.66				.50
Has fear of cancer returning been a problem?			.81			.75
Has fear of cancer spreading been a problem?			.79			.77
Have worries about the future been a problem?			.64			.65
Has fear of death been a problem?			.61	.42		.59
Have spiritual doubts been a problem?				.74		.60
Has guilt or shame been a problem?				.72		.59
Have thoughts of being useless been a problem?				.62		.58
Have worries about sexuality been a problem?					.80	.73
Have worries about appearance after surgery been a problem?					.76	.69
Has stress in your relationship with spouse/partner been a problem?		.48			.52	.58
Extraction Method: Principal Component Analysis. Rotation Method: Varimax with Kaiser Normalization.						
Rotation converged in 7 iterations.						

Table 35

Means, Standard Deviations, and Coefficient Alpha for Psychological Wellbeing Items (N=309)

Variables	# of items	*N*	*M*	*SD*	Min	Max	Coefficient Alpha
Feelings	8	286	1.92	.66	1.92	2.56	.89
Relationships	5	292	1.65	.66	1.35	1.92	.78
Fear	4	291	2.56	.92	1.95	3.09	.82
Meaning	4	296	1.49	.59	1.25	1.92	.65
Sex & Appearance	3	297	1.83	.80	1.56	1.99	.70

Preliminary analysis of psychological wellbeing. A 2 (Access to Treatment) x 3 (Survivorship Phase) x 2 (Age at Diagnosis) multivariate analysis of variance (MANOVA) was conducted using the five Psychological Wellbeing subscales (Feelings, Relationships, Fear, Meaning, Sex & Appearance) as dependent variables. No two-way or three-way interactions were found to be significant. However, when conducting the MANOVA with all three independent variables, the total number of participants was reduced by approximately 40 participants due to missing data. Subsequently, separate analyses were conducted for each of the three independent variables.

Primary analyses of psychological wellbeing items. Table X displays the means and standard deviations of the Psychological Wellbeing subscales by the three independent variables. Separate one-way MANOVAs were conducted for each of the three independent variables using the five subscales (Feelings, Relationships, Fear, Meaning, Sex& Appearance) as dependent variables. Significant results were revealed for Age at Diagnosis, Wilks' Lambda = .92, F (4, 275) = 5.68, p = .00. The effect size for these findings were small, Age at Diagnosis, η^2 = .09. No significant results were revealed for Survivorship Phase, Wilks' Lambda = .94, F(10, 560) = 1.65, *ns,* or Access to Primary Treatment Services, Wilks' Lambda = .99, F(4, 284) = 1.07, *ns*.

As a follow-up on the significant MANOVAs, separate analyses of variance (ANOVAs) were conducted for each of the five subscales. Bonferroni correction was applied to control for familywise error rate. Univariate results revealed significant findings for two of the five subscales for each independent variable, Age at Diagnosis

and Survivorship Phase. For Age at Diagnosis, results showed significant differences for the dependent variables of Relationships, $F(1,281) = 15.68, p = .00$ and Sex & Appearance, $F(1,288) = 12.99, p = .00$. Comparing the means of the subscales revealed younger breast cancer survivors ($M = 1.87$, $SD = .66$) were more likely to have difficulties with their personal relationships than older survivors ($M = 1.56$, $SD = .62$). Younger survivors ($M = 2.04$, $SD = .79$) were also more likely to have greater concerns related to sex and appearance following their treatment completion than older survivors ($M = 1.70$, $SD = .82$) (see Table 36). No significant differences were found pertaining to the subscales of Feeling, Fear and Meaning.

Analysis of Daily Living Challenges Items

Summary of daily living challenges. Women were asked to identify the severity of nine different daily living challenges they may have experienced during breast cancer treatment and following treatment completion. Table 37 provides a comprehensive overview of all nine items and how women rated each symptom related to severity. Table 38 showcases the most common and long-term daily living challenges women identified. Interestingly, the most common challenges were also identified as the most long-term challenges women foresaw. Keeping up with household chores (70.5%), financial difficulties (50.6%), and health insurance (39.6%) were all identified as the most common and anticipated long-term daily living challenges. The common challenges of employment (32.4%) and life insurance (21.1%) changed rank to fourth and fifth when long-term challenges were identified.

Table 36

Means, Standard Deviations, and Frequencies of Psychological Wellbeing Items

Physical Wellbeing Subscales		*Access to Primary Treatment*			*Survivorship Phase*				*Age at Diagnosis*		
		High Access	*Low Access*	*Total*	*Acute Phase*	*Extended Phase*	*Permanent Phase*	*Total*	*Younger Survivors*	*Older Survivors*	*Total*
Feelings (8 items)	*N*	261	38	299	37	94	165	297	140	150	290
	M	2.02	1.91	2.00	2.14	2.12	1.93	2.02	2.03	1.99	2.01
	SD	.67	.73	.68	.55	.72	.66	.67	.59	.74	.67
Relationships (5 items)	*N*	255	37	292	37	92	290	290	136	147	283
	M	1.71	1.76	1.71	1.96	1.71	1.65	1.71	1.87	1.56	1.71
	SD	.66	.68	.66	.77	.62	.63	.65	.66	.62	.65
Fear (4 items)	*N*	263	38	301	38	94	167	299	141	151	292
	M	2.61	2.34	2.58	2.85	2.65	2.49	2.59	2.65	2.51	2.58
	SD	.93	.92	.93	.88	.92	.93	.92	.87	.99	.94
Usefulness (4 items)	*N*	261	37	298	38	93	165	296	141	148	289
	M	1.52	1.40	1.51	1.71	1.50	1.48	1.51	1.57	1.48	1.52
	SD	.62	.50	.60	.59	.65	058	.61	.56	.66	.61
Sex & Appearance (3 items)	*N*	262	.49	299	38	93	166	297	141	149	290
	M	1.85	37	1.86	1.92	1.89	1.83	1.86	2.04	1.70	1.86
	SD	.82	1.94	.82	.89	.85	.78	.81	.79	.82	.82

Table 37

Duration of Daily Living Challenges

		Never been a problem		Short-term problem		Long-term problem that did or will go away		Long-term problem that might not go away	
9 Daily Living Items	*Total*	*N*	*%*	*N*	*%*	*N*	*%*	*N*	*%*
Employment	309	209	67.6%	64	20.7%	13	4.2%	23	7.4%
Financial difficulties	308	152	49.4%	84	27.3%	42	13.6%	30	9.7%
Health insurance	308	186	60.4%	56	18.2%	23	7.5%	43	14.0%
Financial assistance or government benefits	291	242	83.2%	23	7.9%	12	4.1%	14	4.8%
Keeping up with household chores	305	90	29.5%	135	44.3%	47	15.4%	33	10.8%
Finding child care	309	271	87.7%	22	7.1%	0	0.0%	0	0.0%
Life insurance	303	239	78.9%	11	3.6%	14	4.6%	39	12.9%
End-of-life choices	299	258	86.3%	19	6.4%	10	3.3%	12	4.0%
Legal services	296	264	89.2%	15	5.1%	7	2.4%	10	3.4%

Table 38

Most Common Daily Living Challenges and Long-term Challenges

Five Most Common Daily Living Challenges			*Five Most Long-term Daily Living Challenges*		
	N	*%*		*N*	*%*
Keeping up with household chores	215	70.5%	Keeping up with household chores	80	26.2%
Financial difficulties	156	50.6%	Financial difficulties	72	23.4%
Health insurance	122	39.6%	Health insurance	66	21.4%
Employment	100	32.4%	Life insurance	53	17.5%
Life insurance	64	21.1%	Employment	36	11.7%

Factor analysis of daily living challenges items. The nine ABCNAS items assessing daily living challenges were analyzed using principal component analysis with varimax (orthogonal) rotation. Results indicated that a 2-factor solution, accounting for 51.7% of the variance, was the most parsimonious. Factor loadings and communalities are presented in Table 39. Based on the item content, the two factors are best represented by the labels Financial/Economic Issues and Legal Issues. Consisting of seven items, Financial/Economic Issues factor accounted for 31.6% of the item variance. Consisting of three items, the Legal Issues factor accounted for 20.1% of the item variance. One

item loaded on both factors and was included in both factors. Internal consistency for each of the scales was examined using Cronbach's alpha and is presented in Table 40. The obtained alpha coefficients were adequate, .77 for Economic/Financial Issues and .63 for Legal Issues.

Table 39

Exploratory Factor Analysis of Daily Living Challenges Items

Rotated Component Matrix[a]			
	Component		Communalities
	1	2	
Have financial difficulties been a problem for you?	.79		.66
Has financial assistance/government benefits been a problem for you?	.71		.54
Has health insurance been a problem for you?	.70		.52
Has employment been a problem for you?	.66		.52
Has keeping up with household chores been a problem for you?	.51		.28
Has finding childcare been a problem for you?	.47		.34
Has life insurance been a problem for you?	.46	.42	.39
Have legal services been a problem for you?		.82	.75
Have end-of-life choices been a problem for you?		.81	.67
Extraction Method: Principal Component Analysis. Rotation Method: Varimax with Kaiser Normalization.			
a. Rotation converged in 3 iterations.			

Table 40

Means, Standard Deviations, and Coefficient Alpha for Daily Living Challenges Items

Variables	# of items	*N*	*M*	*SD*	Min	Max	Coefficient Alpha
Economic/Financial Issues	7	281	1.57	.57	1.07	2.06	.77
Legal Issues	3	296	1.31	.61	1.20	1.49	.63

Preliminary analysis of daily living challenges. A 2 (Access to Treatment) x 3 (Survivorship Phase) x 2 (Age at Diagnosis) multivariate analysis of variance (MANOVA) was conducted with dependent variables of the two Daily Living Challenges subscales (Financial/Economic Issues, Legal Issues). No two-way or three-way interactions were found to be significant. However, due to missing data, when conducting the MANOVA with all three independent variables, the total number of participants was reduced by approximately 40. Given the lack of significance for any

interaction and the reduction in sample size, subsequent analyses were conducted separately for each of the three independent variables.

Primary analyses of daily living challenges items. Table 46 contains the means and standard deviations of the Daily Living Challenges subscales by the three independent variables. Separate one-way MANOVAs were conducted for each of the three independent variables using the two subscales (Financial/Economic Issues, Legal Issues) as dependent variables. Significant results were revealed only for Survivorship Phase, Wilks' Lambda = .96, $F(4, 578) = 2.75$, $p = .03$. The effect size for this finding was small, $\eta^2 = .02$. No significant results were revealed for Age at Diagnosis, Wilks' Lambda = 1.00, $F(2, 283) = .29$, *ns*, or Access to Primary Treatment, Wilks' Lambda =.99, $F(2, 293) = 1.84$, *ns*.

To follow up on the significant MANOVA, analyses of variance (ANOVAs) were conducted for each of the two subscales. Bonferroni correction was applied to control for familywise error rate. Univariate results initially revealed significant differences for Financial/Economic subscale, $F(2,296) = 3.70$, $p = .026$, of the independent variable, Survivorship Phase. Results did not remain significant with the adjusted alpha level ($p < .025$). Table 41 displays the means and standard deviations for Daily Living Challenges by group variables. No significant differences were found pertaining to the subscale of Legal Issues.

Table 41

Means and Standard Deviations for Daily Living Challenges Items by Variable Groups

Daily Living Challenges Subscales		*Access to Primary Treatment*			*Survivorship Phase*				*Age at Diagnosis*		
		High Access	*Low Access*	*Total*	*Acute Phase*	*Extended Phase*	*Permanent Phase*	*Total*	*Younger Survivors*	*Older Survivors*	*Total*
Financial/ Economic (7-items)	*N*	263	38	301	38	94	167	299	141	151	292
	M	1.59	1.68	1.60	1.70	1.70	1.52	1.60	1.62	1.58	1.60
	SD	.57	.69	.59	.65	.62	.54	.59	.55	.63	.59
Legal Issues (3-items)	*N*	259	37	296	37	92	164	293	138	148	286
	M	1.32	1.54	1.35	1.51	1.36	1.30	1.34	1.37	1.33	1.34
	SD	.65	.69	.67	.89	.66	.61	.67	.68	.67	.67

Chapter 5 Qualitative Research Findings

Phase Two entailed contextualizing the quantitative findings to better understand healthcare providers' perceptions of the barriers and challenges breast cancer survivors face while living in Alaska. To contextualize and expand on the Phase Two findings, 31 interviews were conducted with a variety of healthcare professionals who provide services to breast cancer survivors in Alaska. Through these interviews, perceptions were gained about the unique needs of urban and rural breast cancer survivors.

Brief Synopsis Feedback

At the start of each key informant interview, participants received a brief synopsis of the significant quantitative findings from Phase One. They were asked to review the synopsis and comment on the findings. The vast majority of healthcare providers interviewed were not surprised by the findings, stating results were consistent with what they experience as they work with breast cancer survivors in Alaska.

Participants did give significant attention to the top five most common physical and psychological side effects breast cancer survivors reported experiencing on a short-term and longer-term basis. Providers reported being surprised by the percentage of women who reported experiencing *neuropathy* and *pain* as common physical problems. They were not as surprised to see that women reported *tiredness and fatigue, hot flashes, and sleep difficulties* as common physical symptoms. Related to psychological side effects, providers in general were not surprised about the top five most common psychological problems (*fear of cancer returning, being anxious, stress, feeling overwhelmed, and fear of cancer spreading*), but were surprised to see that some of these symptoms were reported as permanent psychological problems (i.e., perceived never to resolve).

Providers expressed mixed reactions to the physical problem of vaginal dryness and painful intercourse and psychological concern over sexuality being on the perceived permanent list of top five side effects. Some were surprised because anecdotally they had not heard women express concerns about vaginal dryness or painful intercourse. Others stated they were not surprised and highlighted the increased need for providers in general

to make a point to discuss sexual side effects during the course of cancer treatment with their patients. Following their brief reactions to the reviewed synopsis, most providers interviewed preferred to move on to the next question which related to identifying barriers breast cancer survivors face in Alaska.

Qualitative Broad Themes

Based on qualitative analysis of the key informant interviews, a number of themes emerged as healthcare providers discussed their perception of the key barriers and ways of meeting the needs of breast cancer survivors in Alaska. Through the analysis of 31 interviews, 12 significant nodes emerged from the data that were arranged into five broad categories, described as *Breast Cancer Service-Related Barriers*; *Breast Cancer Service, System and Training Gaps; Healthcare Providers' Roles in Breast Cancer Care; Breast Cancer Service, System, & Care Structure Improvements; and Rural Breast Cancer Survivors: Challenges and System Improvements.* The qualitative results are organized along these five overarching themes.

Breast Cancer Service-Related Barriers

Healthcare providers shared information about their perceptions of the primary barriers to meeting the needs of breast cancer survivors in Alaska. Figure 3 provides a visual illustration of the qualitative themes that emerged in the broad category entitled *Breast Cancer Service-Related Barriers.* The following section provides a detailed summary of results formulated in each theme within this category. The themes included *Logistical Barriers, Service Access Challenges, and Information Deficits.*

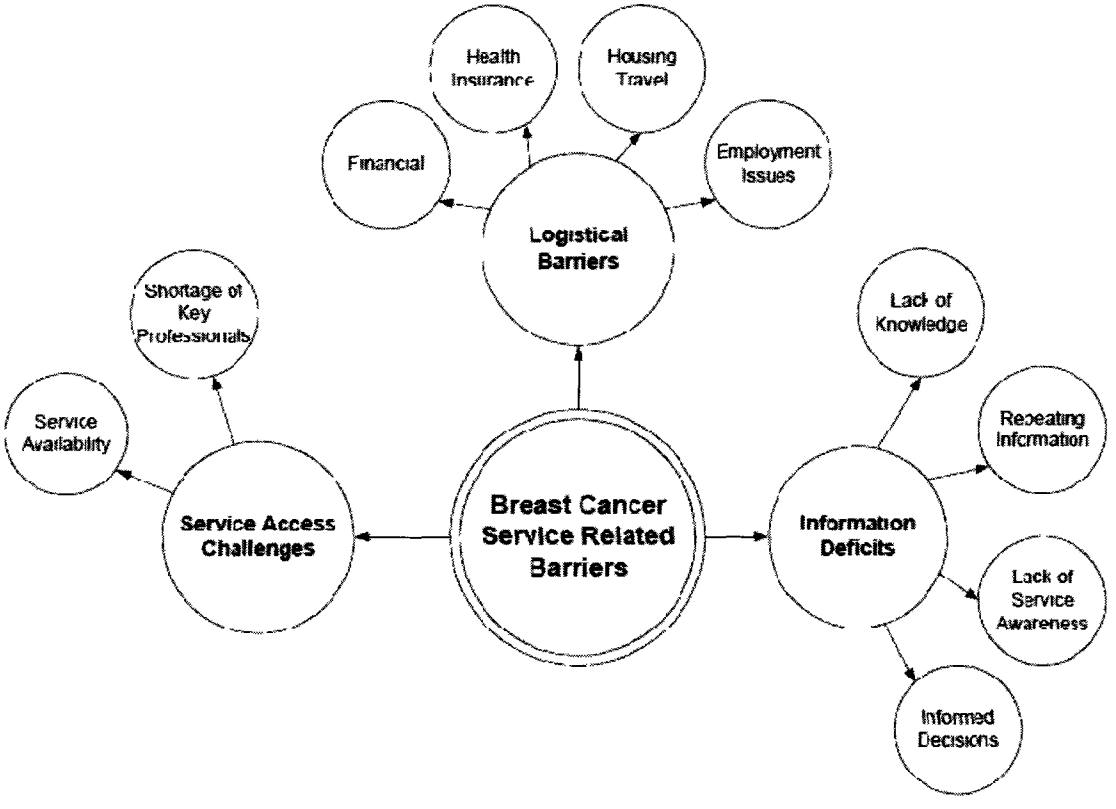

Figure 3. Breast Cancer Service-Related Barriers

Logistical barriers. Healthcare providers overall identified several key logistical barriers that contribute to the additional challenges breast cancer survivors often face. Almost all providers identified that financial barriers can affect not only the survivor, but also her family and loved ones. Overall medical cost of cancer in general was identified as a large impeding financial burden, even in the presence of adequate health insurance coverage. One healthcare provider's words provide a representative description of the financial impact felt by breast cancer survivors and their families.

> *I think financial need, financial resources, people who aren't covered by insurance is a great barrier. Even [having] to pick up 20% of their cost is huge and will bankrupt people. It's very expensive, so I see that. The first things that we see are people are worried about having cancer and I would say the second biggest need is they are worried financially. It doesn't matter if they are people with a lot of resources or no resources. People have to give up their jobs,*

because they are going through treatment and that income stops and they are not used to living without that income.

Healthcare providers identified health insurance as a significant factor that affects meeting the needs of breast cancer survivors in Alaska. Providers expressed their perception that some patients without health insurance frequently fall through the cracks and may not receive the same quality of care as those with health insurance. At the same time, providers identified financial assistance programs available for those who qualify as often very helpful in decreasing the financial burden of not having health insurance to cover the cost of the cancer treatment(s). In addition to financial strain, certain healthcare providers also acknowledged the challenges of working with Medicare and Medicaid and the restraints they feel to conform to their regulations (i.e., 15 minute doctor appointments). As a result of enforced regulations, several providers explained they have opted out of taking Medicare/Medicaid patients. One physician expressed this notion representatively in the following words:

People don't understand that Medicare reimburses for 15-minute visits, and that's a major flaw with our healthcare system. Which is why I've opted out of all government programs, because I can't practice that kind of medicine. Until we're willing to deal with the fact that we have an aging population right now, and that as they get cancer, 15 minute visits are not adequate.

Housing and travel barriers were also frequently mentioned as issues that arise when trying to accommodate breast cancer survivors, especially those who live outside the primary treatment centers (Anchorage, Matanuska-Susitna Valley, and Fairbanks). In regard to housing, currently Anchorage has limited availability for individuals and families who need to be in treatment for an extended period of time. A few providers identified the Hickel House at Providence Hospital as a possible resource where individuals can stay, but noted the cost of $71.00 a night can be expensive for low income individuals and families. Other available housing options identified by providers in Anchorage included Quyana House, which is part of the Alaska Native Medical Center and, available to its beneficiaries. Providers were not aware of housing resources

available in Mat-Su or Fairbanks for individuals currently in treatment. The American Cancer Society was identified as working with local hotels to offer discounted rates to cancer patients who are undergoing treatment and need a place to stay. One provider identified efforts have been made to increase lodging in Anchorage, but were stopped due to the current economic downturn. This individual asserted the following:

> *Right now there was a big push to build a Hope Lodge here. And we raised money to do the study on need and it's kind of stopped because of the economy and taking a look at, can we support it once it's up and running.*

In addition to housing, the issue of travel was identified as a primary logistical barrier for breast cancer survivors. Travel was identified as air and ground transportation. Healthcare providers revealed cancer patients in general often may have difficulty getting back and forth to treatment and doctors' appointments. Providers spoke of a program in Anchorage, coordinated through the American Cancer Society called Road to Recovery, which uses volunteers to provide transportation to cancer patients. Although some Anchorage area needs are being met, providers acknowledged ground transportation needs remain for patients living in outlying areas. Air travel was identified as a major barrier that can delay treatment or needed surgery. The cost of air travel to and from remote areas of Alaska was perceived as a barrier despite several available programs that help with the cost of such travel. One provider representatively stated the following about travel barriers in Alaska:

> *There are some differences and some challenges here because of geography, basically. There are women who are from very remote places that are getting their treatment – having to come into Anchorage or Fairbanks or the Valley from some of these other places can be a stress on them and there are some things - we have had people who have done remarkable things like fly back and forth from Soldotna every day. There are more resources here in Alaska to help people with situations like that than there actually are in a lot of the places in the lower forty-eight.*

The fourth broad barrier identified by healthcare providers was related to employment issues survivors have encountered. Although only five of the 31 healthcare providers identified employment issues as a barrier for breast cancer survivors, the employment issues that were raised were concerning. For example, one provider stated, "I can name at least a dozen people that had a well paying job and they were let go because of their cognitive issues." Another provider who works directly with breast cancer survivors recalled patients' experiences with what were described as hostile work environments. This interviewee elaborated as follows:

> *I find work environments can sometimes be hostile to cancer patients. Some of them start out with borrowed time and everything, but god, it's been six months and it's not over yet. Then suddenly work becomes almost an enemy and adversary. I have someone right now being eased out of employment, in a place we wouldn't expect it. It's just amazing.*

Other providers identified the importance for breast cancer survivors to maintain employment because if they do not, they lose the very health insurance needed to help them cover the cost of treatment.

Service access challenges. A number of challenges related to accessing services were identified by the healthcare providers. Providers identified the need for more key professionals who are well trained to work with breast cancer survivors in Alaska. The shortage of family physicians in Alaska was noted as creating a service gap for survivors following treatment completion. Some healthcare providers were under the impression that Alaska would benefit from more breast surgeons, medical oncologists, and radiation oncologists to improve access to services. Other providers voiced the belief that sufficient numbers of cancer specialists exist in Anchorage, but not in outlying areas of Alaska. Aside from direct medical care, one provider highlighted the need for more trained psychologists who are accustomed to working directly with cancer survivors and the various issues that frequently arise during survivorship. Another provider identified the continual need for more physicians in general to live and practice in Alaska:

> *One of the gaps would be a lack of physicians, because while we have an assortment of them, I don't think that they are all readily available, nor do they have a lot of space, nor do they have a lot of time to really spend time and energy with people. It's sort of a machine, which I think is one of the reasons that people don't get all of the information that they need.*

Healthcare providers also identified the challenge of service availability to women with breast cancer across the state of Alaska. Women in rural areas were consistently identified as having greater difficulty accessing services as compared to urban areas. One provider who practices in rural Alaska indicated survivors had to access some services over the phone, and identified it would be more personable and beneficial to see healthcare providers face-to-face because a survivor is more likely to bring up concerns in a personal contact. This provider strongly asserted that one-on-one contact made a difference for women in terms of treatment adjustment and outcomes. Another provider pointed out that after a woman is diagnosed with breast cancer, she should be able to access providers quickly, not having to wait for months as may occur currently. Although service availability has improved for women who live in urban and rural communities, it remains an area for further improvement. One provider highlighted a host of challenges with regard to service availability in Alaska in the following representative terms:

> *Well, certainly, if the services are not present, then there is no access. If they are present, but they are difficult to access, then that is a problem. If there is no awareness of the services that are present, then that is an access problem. So, all of those, in different ways, are present here in our state. We don't have all of the services that we need and could use. And then - we don't always have the easy access to them, by a lot of women who live in other areas, not nearby; then lack of information either within the provider community, or there is the community at large, makes access more difficult as well.*

Information deficits. The third primary barrier that arose in the interviews was information deficits. Information deficits referred to making informed choices about treatment options, lacking awareness of services available, the need to repeat information to survivors, and general lack of knowledge.

Healthcare providers identified making informed choices about treatment options as an important topic area to cover and a few expressed the opinion that women are not given true informed consent prior to treatments. One provider elaborated on this topic by stating:

> *There have been some women who have said, "Had I understood what this, had I fully understood that I was likely to have this particular symptom this badly, I probably would not have chosen chemotherapy." That is a scary thing to hear but the point is we do informed consent with people. This is an issue that I am very concerned about, that I do not believe that women are given true informed consent when they take chemotherapy and radiation...*
>
> *But I think in informed consents we really should be telling women that the risks are there for these kinds of things. We tell them about, "Here is the medical risk", you are not telling them about really the cognitive and the psychological and the fatigue issues. As scary as that is for people to think that maybe someone might not choose to do chemo, it is still part of their right to choose. I cannot tell you how many women said to me, "Nobody and I mean nobody ever suggested to me, and I didn't see that in the informed consent. If it was there I didn't get it, that this could be what I would be living with four and five years later." They are very clear, the memory was good and now it's not.*

Lack of service awareness was a repeated theme when interviewing healthcare providers. Multiple providers identified they have worked with women who have not been aware of available services. One provider hypothesized the reason some women are not aware of services has to do with information overload immediately following a breast cancer diagnosis. Others interviewees expressed surprise that even though they are out in

the community delivering information about available services they continue to encounter women who are stunned to learn about services available to them outside of conventional treatments (i.e., surgery, chemotherapy, radiation therapy). One provider summarized this issue of lack of awareness of alternative and complementary services as follows:

> *The physical and psychological are fairly interrelated for some people and I think a lot of these services exist but folks either don't hear or don't think they qualify or suffer in silence because they don't think their problem is bad enough. We need to give more people permission to seek out these services that we have.*

With regard to the theme of lack of knowledge, providers identified several problematic areas when communicating with survivors. One provider explained that in working directly with breast cancer survivors, a considerable amount of time is spent providing details about what treatment(s) women are receiving and explaining possible side effects, information that should have been provided through additional education services at the oncology offices who are delivering these treatments. Another provider highlighted the pressure on breast cancer patients to retain information that is presented to them in a hurried manner and that they are expected to use to make key decisions at a time when they may feel in crisis. In a general sense, a few providers lamented that despite the development of better treatments, a general lack of knowledge remains about how to adequately manage the long-term effects of cancer treatments. This lack of knowledge is experienced not just by cancer survivors, but also by their providers.

Related to perceived information deficits is the fact that breast cancer survivors often need to be told information more than once. The majority of providers acknowledged how overwhelming a diagnosis of breast cancer can be for an individual and her family. This sense of being overwhelmed may get in the way of processing and retaining information, especially when it is delivered quickly and only verbally. At least one provider used this phenomenon to explain why some survivors may feel as though they have additional unmet needs despite the fact that services are actually available to meet those needs. Interviewees expressed the need to re-educate women about available services even if there is the perception that the information has already been shared.

Other providers attributed the lack of awareness of services to women needing to be told more than once what their options are and what additional auxiliary services are available that may help them during and following their cancer treatment. Another provider emphasized the importance of having information repeated for women and highlighted the difficulty women have processing information when they are initially told of their diagnosis and possible sequelae:

> *Going back again to my point of, at first point of contact women need to hear what their options are more than once. They need to know that there are places to go and that their doctors will send them there or they can ask. A lot of people say, "Why didn't I know about this?" Well maybe their doctor did tell them but they just couldn't process it. I get that a lot.*

Breast Cancer Service, System, and Training Gaps

Healthcare providers shared information about their perception of the primary service, system, and training gaps that become evident when working with breast cancer survivors in Alaska. Figure 4 provides a visual illustration of the qualitative themes that emerged in the broad category entitled *Breast Cancer Service, System, and Training Gaps.* The following section provides a detailed summary of results formulated in each theme within this category. The themes included *Fragmented Care, Survivors Transitioning to Long-term Care, Training and Education Gaps.*

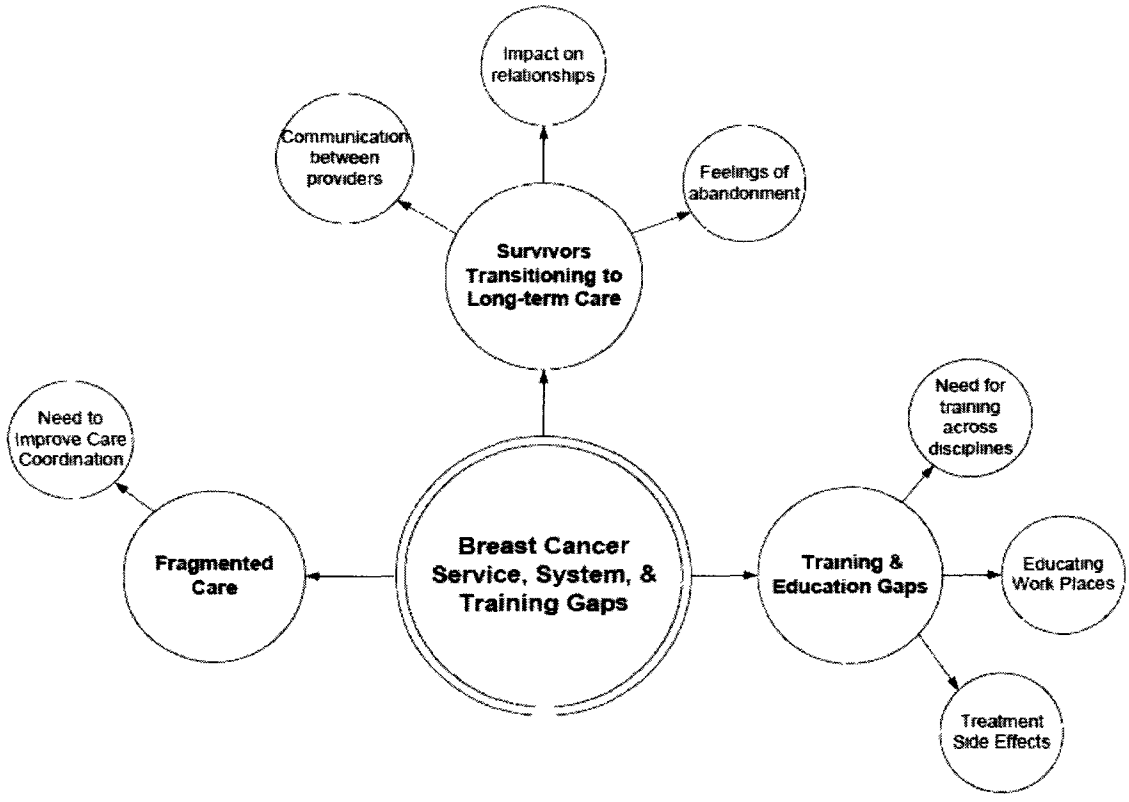

Figure 4. Breast Cancer Service, System, and Training Gaps

Fragmented care. Multiple providers highlighted that although available services have improved and increased over the years for cancer patients in Alaska, care remains fragmented. One provider emphasized cancer patients frequently express the desire to have one central care coordinator in charge of their case. The theme of care coordination of services was identified regularly. For example, one healthcare provider empathized how overwhelming it is for women to track all necessary appointments, especially while they are receiving cancer treatment(s) and are not feeling well. Providers who deliver auxiliary services noted they have patients who would have taken advantage of additional services had they known about them and had someone coordinated access to them. Another provider highlighted how comprehensive cancer centers outside of Alaska manage these issues and compared those procedures to the way treatment is delivered and coordinated in Alaska:

> *I think until recently we didn't take a very comprehensive approach to cancer therapy. If you look online at the cancer centers of America or some of the other*

sites, Mayo Clinic, they have a very comprehensive approach. It's an institutionalized, pre-diagnosis, diagnosis, post- diagnosis and lifelong support and they have pulled in resources from a lot of different areas that are just not surgical or oncologic management. I think we've got very fragmented care up here. That has gotten better and it's the whole motivation to having a cancer treatment center and coordinating the care. But distance in geography makes a difference in how well you can really deliver that.

Training and education gaps. A number of providers identified the need for training across disciplines to make all providers aware of services that are currently available for cancer patients in Alaska. Some of the auxiliary services interviewees highlighted were oncology rehabilitation, naturopathic services, mental health services, genetic counseling, and patient navigation. Providers proposed if training were available and providers took advantage of such education, they would be more likely to refer patients to these existing auxiliary services.

Interestingly, several providers mentioned the need to educate employers about the side effects of cancer treatments and what they can expect from employees who are undergoing or have completed cancer treatment. Providers recalled breast cancer survivors who lost their jobs following treatment completion due to cognitive and other changes that linger long after treatment is considered complete. During the course of the interviews, providers involved with the Alaska Cancer Care Alliance highlighted that one of the Alliance's goals for 2011 is to educate employers in Alaska about side effects and consequences of cancer treatment and what employers can reasonably expect from employees during the course of their cancer journey.

Interviewees asserted that more training and education efforts are needed to inform cancer patients and their families about possible immediate and long-term side effects as a result of treatment(s). Related to physical side effects, one provider strongly advocated for more attention to the severity and long-term nature of cognitive side effects breast cancer survivors can experience following their treatment. Another side effect identified by informants as often ignored was that of sleep difficulty and the need to

educate patients and survivors about sleep hygiene and the benefit of exercise on sleep. Other interviewees acknowledged some survivors have difficulty asking providers for sleep aids when they feel they need them. Fatigue was highlighted as another frequent physical side effect experienced by survivors yet undertreated. Interviewees expressed the need to continue to educate patients and survivors about the benefits of physical activity, nutrition, and relaxation during treatment and following treatment completion.

In addition to physical side effects, psychological side effects were also discussed by providers. One mental healthcare provider commented on the common occurrence of depression among breast cancer survivors. A medical provider acknowledged more could be done to screen for depression and anxiety among cancer patients, explaining a nurse could provide a simple questionnaire to all patients prior to their physician appointment. Results could then become part of the discussion during the medical session. More than half the interviewees acknowledged fear of cancer recurrence as a frequent issue among their patients. At times, providers noted, such fear prevents women from getting follow-up mammograms. Multiple providers identified the great difficulty experienced by survivors as they await results, a time that is highly anxiety provoking for them. Two providers suggested women should not have to wait for results from mammograms and suggested the radiologist read the image on the spot and report the results to the patient immediately. One provider nicely summarized issues related to the psychological side effects of cancer treatment and the need to treat the whole person:

> *We overlook depression as being a normal part of the cancer treatment process, rather than recognizing that depression may be completely new to someone going through cancer. The change in mental health status, the change in anxiety, the change in fear of reoccurrence is talked about in this study, the sleep disturbances, the things that often the medical team may downplay because they are focusing on treatment side effects, missing the whole person.*

In addition to physical and psychological side effects, multiple providers noted sexual side effects of cancer treatment and the reality that these are not addressed adequately by the medical community. Providers highlighted the challenges of cancer therapies that

induce menopause and side effects that may affect women's sexuality. Healthcare providers identified efforts had been made in the past related to educational forums on sexual side effects of cancer, but indicated little attention was being paid to this topic recently. The only resources noted included one oncology nurse, who was recognized as providing lectures to other providers and emphasizing the need to talk to their patients about their sexuality, and discussions about sexuality in support groups. Multiple support group facilitators (who were also healthcare providers) noted they have had discussions in their groups that allowed survivors to voice difficulties they experience in talking to their oncologist or other direct service providers about sexual side effects. Special challenges emerged around topics of vaginal dryness and gaining adequate information about treating sexual side effects. One provider expressed this issue representatively by stating:

> *I am sad to see how little we talk about sexuality in all of the context of the work that we do; it's certainly not my area of training, but I think holding that question about changes of intimacy, sexual identity, sexual practice, comfort levels. I have certainly heard couples share about the pre-surgery, post-surgery changes and yet those are so hushed rather than actively talked about.*

Survivors transitioning to long-term care. Although completing and being finished with cancer treatment(s) is an exciting time, it often brings about confusing feelings of abandonment and fear due to not being monitored as closely by care providers. Several providers noted breast cancer survivors frequently feel as though they have been dropped from the healthcare system and while they are glad to be done with treatment, they miss the security of being closely monitored. One provider explained this dilemma as follows:

> *There is a very significant relationship that occurs between a woman and her oncologist. I've heard patients say to me that they feel, even though they are the ones leaving, they feel somewhat abandoned. Patients feel a little bit lost when they say, "I'm not going to see my doctor, I don't have to come back now I was going every three months and I don't have to come back for six months."*

A few healthcare providers who themselves are breast cancer survivors recalled the difficulty they encountered transitioning to long-term care and the challenges this transition entailed. They described feeling as though a meaningful relationship had ended and they were expected to move forward without adequate closure. This transitional period was highlighted as a pivotal time for breast cancer survivors to reach out to peers, attend support groups, and communicate with primary care physicians about their difficulties. One provider described this phase of treatment as "a vulnerable time when women don't feel whole yet."

In addition to the cancer survivor, the survivor's partner and family members can also have difficulty adjusting to being finished with cancer treatment. One provider who works with cancer survivors and their families commented:

> *In caregiver groups too, by that I mean husbands, wives, mothers, so that population also like, "Well, what do we do now? We were in this significant relationship and now they are discharged, it's over. How do we go back to just being husband and wife, how do we go back to being boyfriend, girlfriend, how do we going back to being mother and daughter, when all I have done is worry about her for five years?" There are other systems that are impacted that transcend the medical systems.*

Another challenge mentioned in the context of transitioning to long-term care was communication between the primary care provider (PCP) and cancer specialist. When speaking to cancer specialists they stated they make an effort to copy the patient's PCP on various reports that are transcribed and emphasized the importance of keeping the PCP in the loop vis-à-vis the patient's cancer care. Providers mentioned that frequently, especially in cases of advanced cancer, the medical oncologist becomes the patient's PCP because of their frequent contacts. Another provider stated because cancer specialists see so many patients from out of town they often address other issues outside the immediate cancer care because it is easier for them (than for other providers) to keep a close eye on the patient. One family medicine physician explained this situation as follows:

> *Right now the communication link between the primary care providers and the*

oncologists is almost a full disconnect. It's almost like a patient gets diagnosed and they just get dumped off. Because of that, the oncologists can't completely manage everything. I think that healthcare providers as a whole -- I would like to see the state medical association set as a priority one year, to have a primary care provider discussion or education offering about, "How do you take care of your cancer patients," because they are still your patients.

Healthcare Providers' Roles in Breast Cancer Care

Healthcare providers perceived multiple roles for healthcare providers who work with breast cancer survivors in Alaska. Figure 5 provides a visual illustration of the qualitative themes that emerged in the broad category entitled *Healthcare Providers' Roles in Breast Cancer Care*. The following section provides a detailed summary of results formulated in each theme within this category. The themes included *Increase Referrals to Auxiliary Services, Improve Awareness of Additional Services,* and *Communication with Survivors.*

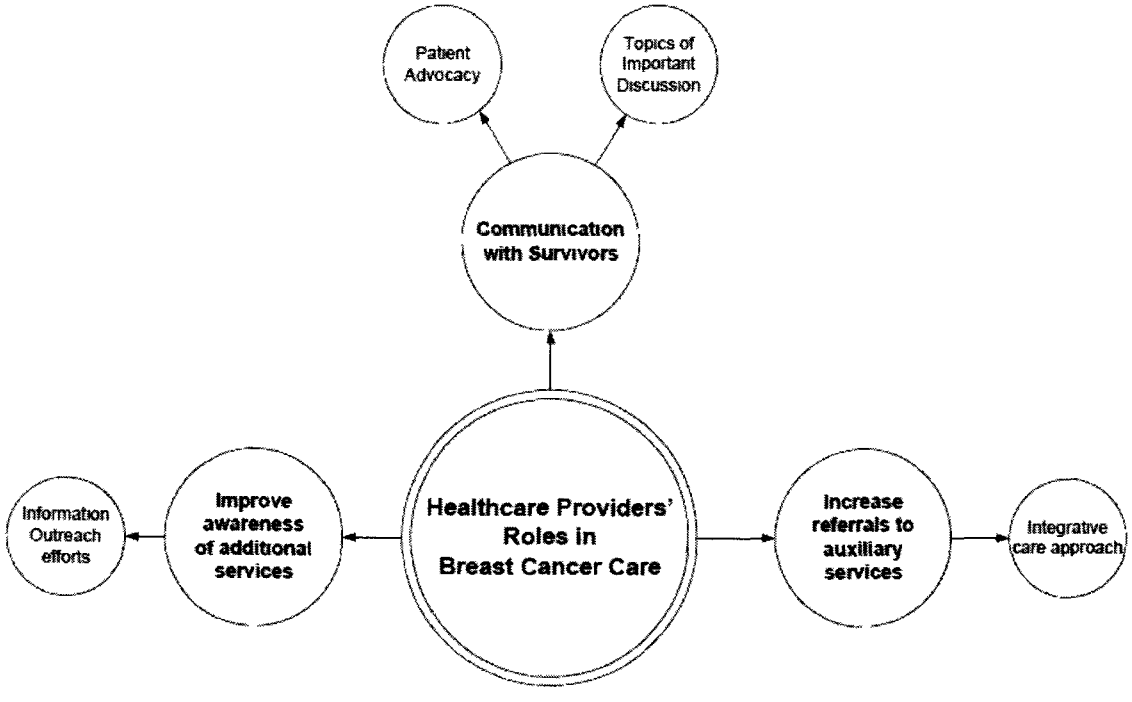

Figure 5. Healthcare Providers' Roles in Breast Cancer Care

Increase referrals to auxiliary services. Providers identified a need for an increase in referrals to auxiliary services. One provider would like to see every patient receive an intake that focuses not only on treatment plans, but also strives to address psychosocial needs of patients. If such needs are identified more systematically, more referrals to appropriate services are possible. Other providers called for integrative care approaches that tailor services to needs. One example mentioned was for direct service providers to be willing and open to referring to alternative and complementary treatments (e.g., naturopathic services) as adjuncts to conventional therapies. Additional referrals areas highlighted included more referrals to oncology rehabilitation, genetic counseling, counseling services, and dietary services. Providers lamented it is difficult to increase referrals among medical oncologists and breast surgeons because in Anchorage and the Matanuska-Susitna Valley their practices are private and are not officially part of the cancer centers at the hospitals. One provider identified the need for a more integrative approach to cancer care in Alaska:

> *I think one of the things that I would like to see changed is more of an integrative approach so that physicians as well as nurse practitioners and nurses and office staff and anybody that comes into contact with somebody dealing with cancer has more information or at least knows where to send people to get more answers.*

Another provider of supportive services to breast cancer patient expressed the opinion that more medical doctors are needed for referrals and highlighted the important role they play with breast cancer survivors:

> *I think in some ways MD does stand for medical deity, not that they have all the answers but they are seen by a lot of patients as the final, most magnificent resource. If they are not sharing anything except their tiny little piece of the pie, then I think we are missing out because I think they could have a lot of power in what they do suggest. If they were putting more information out and I realize that is asking a lot of them too, that would be delightful.*

Improve awareness of additional services. One provider explained the reason more referrals are not made may be that providers are not aware of available services. A

supportive care provider voiced frustration with going to medical offices and infusion centers to deliver information about available services; yet medical providers continue to not refer their patients to these services. Another provider asserted that general healthcare providers, regardless of specialty, need to be committed to continuously augmenting and updating their own knowledge, learning about resources in the community that may help to better serve their patients, and distributing up-to-date information appropriately and effectively. Another interviewee highlighted the importance of not only being aware of services available, but disseminating the information in an effective way that is useful and memorable for patients. One participant who works in rural Alaska voiced concern for providers to be aware of available services and the need to make appropriate referrals because individuals from rural areas may not have opportunity or knowledge to know where to gather the information. This interviewee explained patients primarily rely on their direct medical provider to give them any additional helpful information, generally not seeking this out on their own.

Providers mentioned efforts have been made to increase awareness of services available to breast cancer survivors. Oncology providers stated they provide breast cancer/cancer care kits to their patients that contain a host of information. Another provider reported frequent encouragement of Mary Katzke's films (Katzke, 2007, 2010) for patients to watch the journeys of different breast cancer survivors in Alaska and other part of the United States. The American Cancer Society, Alaska Cancer Care Alliance, and State Comprehensive Cancer Control offices were credited with providing information, attempting to network, and striving to raise awareness about information, lectures, and programs available to cancer patients and their families within the community.

Communication with survivors. The way in which providers communicate with breast cancer survivors can make a huge difference in their patients' entire cancer experience. A few providers highlighted the importance of active listening, through which, despite the physician's time constraints, they can ensure that patients feel heard

and understood. Multiple providers identified the need to discuss topics of importance that included asking about personal relationships and other support resources, discussing possible sexual side effects, and screening for depression and anxiety. It was emphasized that if providers felt more comfortable discussing these topics it would give women permission to express any concerns they may have related to these areas. Another provider expressed the importance of helping patients feel safe when communicating with them. Interviewees suggested actions such as orientating patients to a given clinic or office to help them feel comfortable. One provider expressed the importance of paying attention to the provider-patient relationship as follows:

> *If you have a relationship with someone, if you communicate with them, if you spend time with them, if there is any sort of connection then I think that will only help to improve the follow up care and survivors' ability to process. To follow through and most importantly to continue the follow up care if they feel connected.*

Two providers (who also facilitate support groups) highlighted the need for oncology offices to hire compassionate and kind staff and nurses, noting the importance of patience when working with cancer patients and their families. Related to communication, one provider emphasized the importance of survivors hearing information not only from providers directly, but also from other personnel in medical offices. One direct medical provider urged providers to tell patients they need to advocate for themselves within the healthcare system and noted providers need to teach patients how to advocate for themselves. This interviewee summarized important points as follows:

> *What I find is women who are more out there in the world, maybe more used to advocating for themselves have better access. That is just unfortunately, just the way it is. I do think advocacy maybe even some education on how do I advocate for myself. How do I go about doing that, people in your face with a medical crisis you don't know what you need to do to advocate, until there is a problem.*

Breast Cancer Service, System, and Care Structure Improvements

Participants shared perceptions of the service, system, and care structure improvements necessary to better meet the needs of breast cancer survivors in Alaska. Figure 6 provides a visual illustration of the qualitative themes that emerged in the broad category entitled *Breast Cancer Service, System, and Care Structure Improvements.* The following section provides a detailed summary of the results formulated in each theme within this category. The themes included *Addressing Survivorship Needs, System Changes, and Auxiliary Services.*

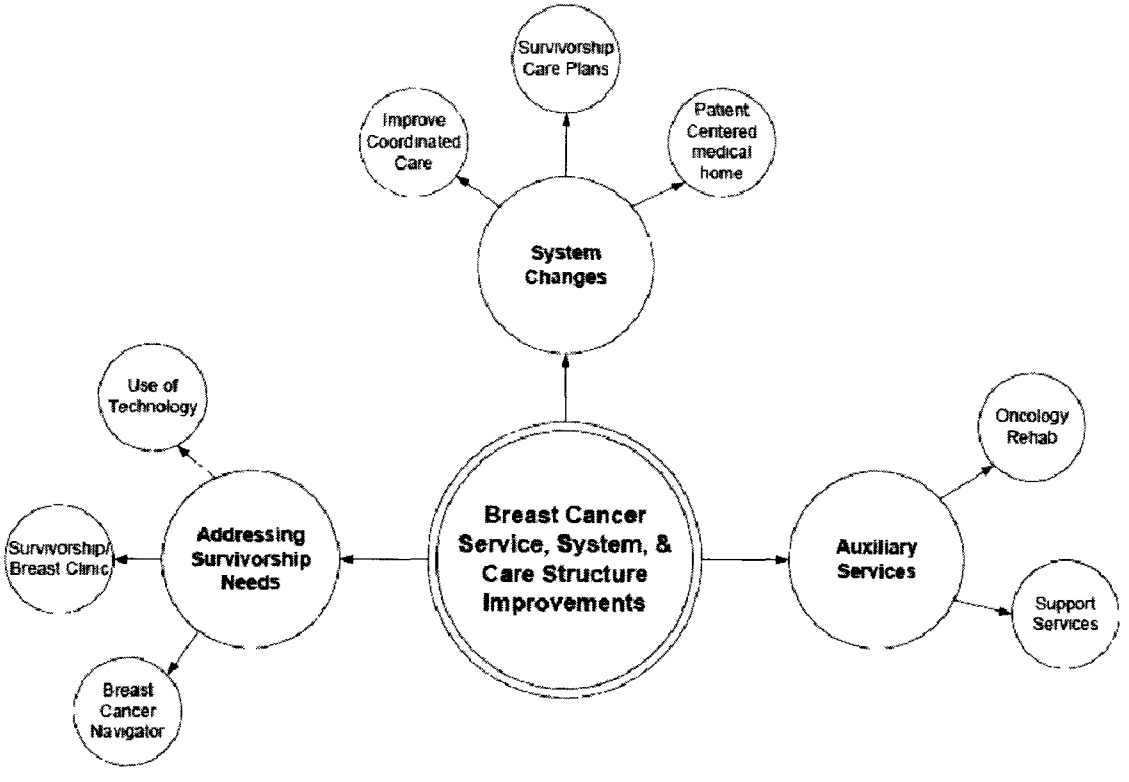

Figure 6. Breast Cancer Service, System, and Care Structure Improvements

Addressing survivorship needs. The need to increase patient navigation was identified by multiple providers. Providence Health System was highlighted as a care system that is planning to hire a breast cancer navigator whose job will be to work with breast cancer patients to coordinate their care. Participants suggested social workers or mental health counselors could be added to each private oncology medical office to improve care coordination and service patients' psychosocial needs.

Several providers mentioned at one time there was a plan to have a "breast cancer clinic" in Anchorage, but the inability to coordinate all necessary participants resulted in the clinic not being formed. Relatedly, one provider mentioned the development of a "survivorship clinic" where cancer survivors could be supported and where short-term and long-term symptoms and treatment side effects could be treated and monitored following cancer treatment completion.

Use of technology was a theme that arose as a way to better meet survivors' needs. One provider gave the example of a patient who used her iPhone to record doctors' visits and consequently could play back information given to her by her provider. This use of recording devices was identified as a way for women to recall information told to them initially but may not have been retained during this emotional time. Another provider, a breast cancer survivor, used an MP3 player to record her surgeon following her mastectomy when she was in the recovery area. She explained she was able to make copies for her family and keep them in the loop of what was going on medically without having to repeat all the information verbatim. She suggested all oncologist offices' have electronic recording devices for patients to use as an option for gathering and storing information.

System changes. When thinking about the challenges of incorporating system changes, one provider emphasized the perception of how best to implement change within an already established care structure. This individual stated that:

> *I'll tell you the truth: the best way for something to happen is to have a regulation come down about it. I know that sounds horrible. When the COC put out the new standards saying there will be survivorship plans in every facility, there will be this, there will be that; if you want to be accredited. That kind of information forces the administration to take action. I know that sounds horrible because we all want patient satisfaction, but the warm fuzzies don't pay the bills. But having the accreditation as a COC accredited facility is important to our facility. It's not that the patients aren't important, but the accreditation, those federal standards and regulations are forcing some change that will help survivors.*

Every participant was asked specifically about thoughts on survivorship/cancer care plans and how they were currently being used in Alaska. The majority of providers were not familiar with survivorship care plans and indicated to their knowledge such plans were not actively being used in Alaska. One general practitioner had experience receiving a care plan and treatment summary from the Mayo Clinic and had found it to be very useful in providing follow-up care to the patient; this participant had not received similar support for breast cancer patients who had been treated in Alaska. Interestingly, the majority of providers were in favor of having a standardized survivorship care plan, but were not sure how the use of such plans could be implemented. A few participants mentioned they encourage women to develop a "survivorship binder" that includes providers they have seen, surgery details, medication regimens, lab test results, and any auxiliary services received. This binder was intended to track information that would be useful when the survivor transferred back to a general practitioner. Another healthcare provider, a breast cancer survivor, explained physicians are not paid to complete something like a survivorship care plan and incentives from insurance companies would be necessary for physicians to do so. One provider commented on the usefulness of an end-of-treatment summary and the challenges of making general system changes:

> *The efforts to add end-of-treatment summaries and to try to have documents and tools that survivors can use, hasn't advanced to the place that I thought it would by the end of 2010. It still is not as complicated as a process as we have made it out to be but I think when we think about systems changes trying to make some uniform end of treatment summaries or help women have templates that they can organize their own information and teach that would be a huge help.*

Another recommended system change was to improve coordinated care of cancer-related services. As noted above, interviewees acknowledged cancer care in Alaska remains fragmented despite efforts to have a "cancer center" in Anchorage. One provider explained representatively the importance and benefit of achieving more coordinated care:

If you have a linked system between hospital services, specialty care, outpatient support services like home health and Hospice and primary care- those four areas and that the payer system pays to keep people as healthy as possible instead of pays for the number of visits you have to the ER or the number of procedures you have or the number of admissions you have, that would drive it back to a more coordinated system.

Although providers identified that cancer care in Alaska is fragmented and in need of coordinated care, few were able to provide specific examples of how to make such improvements. One provider referenced the need to incorporate a patient-centered medical home as a way to increase coordinated care. This individual explained:

A patient-centered medical home model makes excellent sense when you are looking at cancer care because you have got a medical home that coordinates your care. Then you expand that into hospital services and specialty services, but you still have a home to go to. Most primary care practices of the traditional type, provide that to a certain degree. They may not be able to document the outcomes or have as coordinated of a breadth of services, but it's the same concept.

Auxiliary services. Several auxiliary services were identified as helpful for improving services for breast cancer survivors in Alaska. Numerous providers asserted oncology rehabilitation services make a large difference in patients' quality of life and greatly appreciated efforts of educating patients and families about the benefits of physical activity, nutrition, and relaxation. One provider specifically stated that all breast cancer survivors would benefit from attending oncology rehabilitation and providers needed to do a better job of motivating patients to attend and making the necessary referrals.

Support services (such as one-on-one peer support and attending support groups) were identified as beneficial to breast cancer survivors' experiences whether they are in treatment or post-treatment completion. One healthcare provider suggested pairing individuals who are several years out from their cancer diagnosis with patients who are

newly diagnosed. The emphasis was placed on the benefit of one-on-one peer support and how the process of mentoring could potentially help the newly-diagnosed individual to prepare for treatment and other challenges that may arise. Other participants revealed they often offer one-on-one peer support by informally pairing newly diagnosed patients with patient(s) they know who are several years post-treatment completion. It was briefly mentioned and made apparent that not all cancer care providers were familiar with the American Cancer Society's program Reach to Recovery, which pairs breast cancer patients with survivors who have been through a training program about how to mentor patients at the beginning of their cancer journey. One provider stated representatively that:

> *I certainly would love to see more survivors trained to do Reach for Recovery because I think that phone-based Reach support can happen to every community as a real gift that doesn't necessarily need to cost a lot of dollars to do that, but can be one of the tools and the outcomes to really encourage, if Reach is taken up really all over the world.*

In addition to one-on-one peer support, interviewees emphasized the importance and need for cancer support groups. Support groups were described as a good form of connecting survivors and providing a place to share information. Interestingly, nine of the 31 providers offered support groups for various groups in the Anchorage area. As healthcare providers and support group facilitators, they all expressed the benefits of group settings. One support group facilitator described support groups in the following way:

> *Well, and also not only support, but assistance in making decisions so it's giving information and it's hearing other people's experiences to help you make your own decision. It's one thing to read something in a book; it's another thing to hear from a surgeon, but to come to group where you can see somebody's mastectomy site, you can ask them first hand, "How was this?" "What would you do differently?"*

Rural Breast Cancer Survivors: Challenges and System Improvements

Participants shared perception of challenges and possible system improvements when working with rural breast cancer survivors. Figure 7 provides a visual illustration of the qualitative themes that emerged in the broad category entitled *Rural Breast Cancer Services: Challenges and System Improvements*. The following section provides a detailed summary of the results formulated in each theme within this category. The themes included *Logistical Barriers, Need for More Support Services, Access to Services and Communication with Providers.*

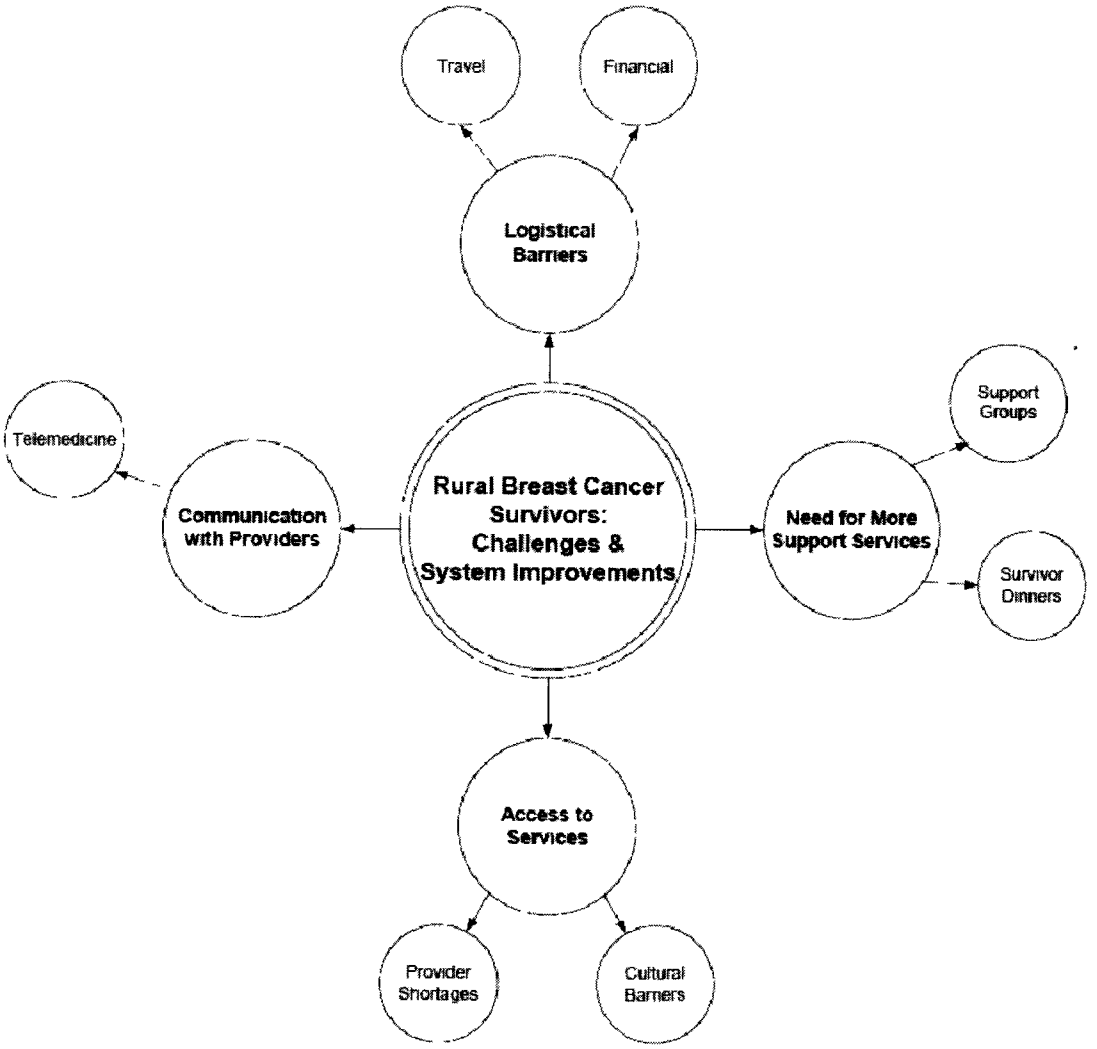

Figure 7. Rural Breast Cancer Survivors: Challenges and System Improvements

Of the 31 participants, only three currently lived in rural areas of Alaska. However, the majority of healthcare providers interviewed had direct experience working with breast cancer survivors from rural Alaska. Living in rural areas of Alaska offers a unique set of circumstances and barriers for both healthcare providers serving rural breast cancer survivors and for those women who reside in rural Alaska.

Logistical barriers. When asked about barriers for breast cancer survivors in Alaska, almost every participant identified financial strains and travel as enormous challenges for patients living in rural areas. One provider who lives in rural Alaska and is a breast cancer survivor explained she ended up receiving her treatment out of state because it was more economical for her and her family. She explained while necessary treatments were available in Alaska, it was a larger financial burden to travel to Anchorage and stay for the course of treatment. One financial strain that affects many individuals living in rural areas is the cost of fuel. One provider stated in trying to coordinate travel arrangements that boats, snow machines, and four-wheelers are often used for transportation; the cost of fuel affects how often they are available for travel. The same provider discussed differences in working with Alaska Native and non-Native breast cancer patients and how patients within the tribal system tend to have less financial stress and better coordination of care than those outside the system.

Multiple providers identified the challenge of travel for rural breast cancer survivors. Due to Alaska's geography, travel is unpredictable and often appointments are missed due to an array of travel circumstances. The challenge of travel was also identified as a barrier to successful follow-up care. Providers expressed the challenge of needing to do advance planning for women to make follow-up appointments in a timely manner. Participants revealed that women who have to travel for their cancer care often end up waiting longer for surgeries, treatment, and follow-up care appointments. One provider representatively described the logistical challenges of servicing rural breast cancer survivors as follows:

> *So, I think I would have to say I do notice that with others too because it's a major, it's not like you are going in for a week for surgery and coming home.*

Your treatments are longer term so, maybe there is a longer gap than you would ideally like for all, native and non native. Although we try to move them in as quickly as possible, they have to find child care... Yes, the logistics are much more intense, I think.

Another barrier identified by interviewees with experience working with rural breast cancer survivors is the fear of coming to Anchorage (Alaska's largest city). One provider explained:

I think, always what is typically a barrier is a fear of coming to Anchorage. We don't think anything of it, but this is, even Bethel is overwhelming to people. Our biggest village is Hooper, that is 1700 people, and our smallest would be like Lime village and there is maybe 30 people. When you come to Bethel and then you bring them on a plane and they are in Ted Stevens Airport kind of like oh my gosh, they told me what to do but... Does their brain make them casually go from C9 down to security, out the door, down to baggage, things that we don't think anything of because we are so used to it.

Need for more support services. The need for additional support services was identified as a service gap that needs to be filled. One participant revealed when she was going through her own breast cancer treatment she was interested in attending a support group or being involved in a program like Bosom Buddies (Bosom Buddies, Inc., 2011). She was shocked to learn that no such services were offered in her hub community. Other providers expressed the need to provide additional support services to rural breast cancer patients following treatment completion. One provider stated although survivors are closely followed for a while after treatment completion, when the phone calls stop, survivors may feel forgotten or that their concerns are no longer valid due to how much time has passed. Another provider who identified the need for more support services in rural Alaska suggested the use of web cameras as a mechanism for communicating with others without having to be physically in the same location.

One provider who works primarily with Alaska Native oncology patients suggested offering "Survivor Dinners" where once a year the community gathers to honor

and acknowledge cancer survivors in the community. A few such dinners have taken place in rural Alaska and encouraged support and bonding. This participant explained when survivors tell their stories at such gatherings, it offers a place for patients to heal and feel supported by others who have shared in their journey. Another provider identified the need for a rural cancer survivor organization that would bring people together from surrounding villages to provide support and share stories.

Access to services. Providers identified living in rural Alaska is challenging for breast cancer survivors in part due to the shortage of specialists and general practitioners. One rural healthcare provider acknowledged the biggest services gaps is not having in-house radiologists immediately available to review mammograms. Another provider identified a gap in services for older breast cancer survivors who are not healing well from surgery or treatments. The importance of staying close to home where their family and friends are available for support and assistance was emphasized. Another deficit mentioned was access to hospice care and the need for developing hospice services in rural hub communities.

Participants reported women from rural Alaska as more likely to elect to have mastectomies or even bilateral mastectomies when they have to choose between a lumpectomy and a mastectomy. One direct medical provider explained the possible reason for this decision-making:

> *The fact that a higher number of our [rural] patients, percentage wise, opt to have mastectomies as opposed to lumpectomy. There are a lot of theories about that, the most prevalent theory is the subsistence lifestyle – time; six to eight weeks in Anchorage to get post operative, post lumpectomy radiation therapy is not in their best interest. Being away from home and, especially if it's a subsistence season - it's not a good thing and that is probably correct.*
>
> *There is probably something about that, but there may be more to it than that as well. It's possible that our [rural] patients are not as concerned about loss of body parts or loss of the breast as maybe other people are, I don't know that. It's*

just my own observation that many patients have opted for bilateral mastectomies even though there was no cancer in the other breast. It was like, you know there are risks so, 'I don't want to worry about it'.

Several providers touched on cultural and stigma-related barriers that used to occur for generations and for some continue to exist. Patients' perceptions of cancer can prevent them from accessing screening and treatment. One provider gave a brief history of how Yupik people used to view someone with cancer, explaining people with cancer were considered "teplek" which means, people who stink or have a smell. If people were "teplek," they were ostracized by the community, isolated, and eventually died. Consequently, people feared becoming "teplek" by being diagnosed with cancer. The provider asserted it has taken years to break down such cultural barriers and it was still necessary to reassure patients that cancer did not result from a character flaw and that not much could have been done to prevent the disease. Another provider with experience working with Yupik people in rural Alaska told of patients not wanting to tell family members they have cancer. An example was offered of a young Yupik woman saying, "please don't use the cancer word in front of my 80-year old grandma." As a result of cultural barriers, providers have learned to use language that is comfortable for their patients while still impressing the severity of the illness.

Communication with providers. One participant, a nurse manager, described getting calls from other providers asking for advice about how to handle patients who . they "think want to talk to you about this but they don't know how to ask." Due to her professional role as well as being a breast cancer survivor herself, she is someone with whom community members feel comfortable talking about cancer-related concerns. This participant emphasized the need to build relationships and trust necessary for patients to open up with questions and concerns. Another interviewee with rural experience identified cultural challenges in working with cancer patients in hospital settings, revealing:

First you had to get people to trust you enough to come and then to open up communications and move forward. They are also not so used to being on a strict

timeline. It's almost like now, when I am working with a lot of the Natives at the hospital, number one they don't speak up.

Two - that is part of it, even though maybe they don't trust the whole process, they still don't say things, they just go along with it; even deal with a lot of pain or a lot of things because they just don't know. I have just run into that over and over and have to be an advocate for them and ask more questions, the right questions, in the right way in order to get what they really feel about the process. They will just deal with it sometimes. So I see that as being a barrier. And providers not know that or not knowing how to maybe get around it.

Regarding communication, a number of providers stated they follow up with rural patients by phone, a form of communication that presents several limitations. One provider explained patients are less likely to disclose symptoms they may be experiencing when the conversation occurs over the phone. This participant stressed the importance of being able to see body language and get an idea of how the patient is doing in person. Another interviewee acknowledged telephone communication has drawbacks, but pointed out that benefits accrue as well. More specifically, this interviewee reported that even though conducted over the phone, the patient receives at least some follow-up care that may otherwise not be possible or practical. Relatedly, several providers identified the need to use telemedicine better to follow cancer patients in rural Alaska. They acknowledged the technology exists, but implementation has been slow to progress. They expressed hope that this is an area of development that will grow in the future.

Chapter 6 Discussion of Quantitative and Qualitative Findings

Integrating quantitative and qualitative methodologies allowed for increased depth and breadth of information from which to draw meaningful conclusions. Conclusions drawn from this study provided significant guidance for developing purposeful recommendations to meet otherwise unmet needs of breast cancer survivors in Alaska. Through the use of an explanatory mixed methods design, the overall purpose of the study was to examine the needs of breast cancer survivors in Alaska from survivors' and healthcare providers' perspectives. The goals of the current study included the following five areas of interest:

1. increase knowledge about the experience of Alaskan breast cancer survivors living in urban and rural areas;
2. increase information about services needed to better meet the needs of women with breast cancer living in Alaska;
3. explore and contextualize providers' perceptions of the needs of breast cancer survivors in Alaska;
4. develop an understanding from healthcare providers as to how the needs of breast cancer survivors in Alaska can be met; and
5. develop recommendations for providers, hospital groups, and key community stakeholders about how to improve services to further meet the needs of breast cancer survivors.

The following discussion sequentially identifies findings and interpretations from the quantitative Phase One and then the qualitative Phase Two. It integrates findings to lead toward recommendations and implications. Results from this study are most meaningful and best appreciated a nuanced manner. For Phase One, given that findings were somewhat varied based on separating the sample into three groups (survivorship phase, age at diagnosis, and access to primary treatment services), summary information is presented based on the ABCNAS domains.

Phase One Findings and Interpretation

Breast cancer treatment and services. Women who completed the ABCNAS received the fewest services in the areas of Alternative and Complementary Services, Formal Psychological Services, and Organized Support Services as compared to all treatment and services domains. It is important to note that lack of received services does not necessarily mean there are unmet needs in these areas. Rather, the findings show the array of services received and what other services could be offered that may be beneficial when women are facing breast cancer. The fact that women received the least amount of services in these auxiliary services may indicate a need for healthcare providers to make more referrals to such services.

Findings indicated that women in the permanent phase (three or more years post-diagnosis) were more likely not to receive services in the form of online support groups or telephone support hotline. Women may have found a decreased need for these types of support services after time had passed from their initial diagnosis and treatment completion. Thewes and colleagues (2004) found few women who identified the need to access support groups after treatment ended. Instead, women reported there was a need to 'move on' and regain their sense of normality (Thewes et al., 2004).

Older survivors were more likely not to receive services related to massage, exercise, and yoga compared to younger survivors. Previous qualitative research has found younger women discussed the use of complementary therapies and changes in diet and exercise more than their older counterparts (Thewes et al., 2004). For formal psychological services, older survivors were less likely to receive services related to counseling for their children. Women over the age of 50 may have less need to seek such services because their children are more likely to be grown and can seek such services independently.

Need for additional information about breast cancer treatments and services. When seeking additional information about treatment and services, women preferred to obtain information about breast cancer treatment and services through consultation with their healthcare provider(s). This finding speaks to the importance of the provider-patient

relationship and the information that is offered during direct provider office visits. The finding is particularly important given that previous research which has shown effective physician-patient communication is positively related to patients' health outcomes (Kiesler & Auerbach, 2006).

When differences were explored between groups, older survivors were more interested in obtaining information about *Common Breast Cancer Treatments* than younger survivors. Overall, older survivors were more interested in seeking additional information about all treatment and services domains, but received fewer cancer-related services as compared to younger survivors. Younger survivors may have sought additional services on their own and taken initiative to do their own research about common breast cancer treatments, thus not feeling as though they needed additional information. Allen, Petrisek, and Laliberte (2001) found younger breast cancer survivors (< 50 years old) were engaged in information-seeking behavior related to asking questions of their physicians, reading the medical literature, immersing themselves in lay publications, and talking to other breast cancer survivors in an effort to gain a better understanding of their disease. Perhaps there is a cohort effect operating in which younger women are more likely to access information through the internet and subsequently indicate less interest and need for treatment-related information than the older cohort who may not have the same comfort and facility with technology. The finding suggests more efforts could be made to ensure all breast cancer survivors are well informed of available cancer-related services, particularly common breast cancer treatments.

Physical wellbeing. When differences among survivorship phase were examined, women in the extended phase (1 to 3 years) were found to experience more symptoms related to pain and fatigue than survivors in the acute or permanent phase, which did not differ significantly from one another. When women are actively in treatment, their pain and fatigue symptoms may be more immediately addressed by their provider as they are more readily expected to occur. This may not be the case for women who are in their extended phase (a year or more after treatment completion) when pain

and fatigue may not appear to be as significant to the provider or may not be viewed in the context of being a reportable sequelae by the patient. Ng and colleagues (2007) discussed the implication of cancer-related fatigue and acknowledged it may persist for years after completing treatment. Janz and colleagues (2007) found fatigue to have profound negative effects on quality of life following breast cancer treatment. In addition, Chang and Sekine (2007) discussed the frequent occurrence of pain among cancer survivors and identified that pain following breast cancer treatment can last long after treatment is completed. The current sample of women expressed similar concerns. Overall, women identified tiredness and fatigue as the most common physical problems, followed by pain as the third most common symptom that affects their physical wellbeing.

Psychological wellbeing. When differences among survivors were explored in the context of age at diagnosis, the current study revealed younger survivors (< 50 years old) were more likely to have difficulties with personal relationships than older survivors. Walsh and colleagues examined young breast cancer survivors and the impact of the disease on their relationships with spouses and children. For spouses, breast cancer was shown to induce distress in relationships and the majority of women experienced problems related to sexuality (Walsh, Manual,& Avis, 2005). Clearly, breast cancer not only affects women, but also their partners. Previous research has found that emotional support from the relationship partner of young women with breast cancer is important to their adjustment (Baucom, Porter, Kirby, Gremore, & Keefe, 2006). These findings highlight the need for women to be asked about the quality of their relationships in the midst and following treatment completion. In addition, services such as support groups and counseling should be offered not only to the woman facing breast cancer, but also to her partner.

Younger women also reported greater concerns with sex and their appearance than older survivors. For younger women, the effects of surgery and removal of the breast have been shown to result in more negative feelings regarding body image (Baucom et al., 2006). Breast cancer and its impact on women's sexuality have been well

documented (Anllo, 2000; Henson, 2002; Huber et al., 2006; and Meyerowitz et al., 1999); however, less research has looked specifically at the impact of breast cancer on younger women's sexuality. When younger women were interviewed, Thewes et al. (2004) found pre-menopausal women experienced gynecological effects of treatment including irregular or painful periods, vaginal dryness, and loss of libido. Several women in the same study reported that they felt as though their breast cancer experience had a lasting impact on their intimate relationships and sexuality (Thewes et al., 2004). Based on the reviewed literature, it is no surprise that in the current study women identified vaginal dryness, painful intercourse, and worrying about sexuality as the fourth most common long-term physical and psychological symptoms they experienced as breast cancer survivors. The reviewed literature and study findings reiterate the importance of asking women about sexual issues that may arise during and following breast cancer treatment and providing education that may be beneficial to their sexual health. The findings from Phase One suggest age at diagnosis is a meaningful variable that must be kept in mind when conducting research and developing treatment programs for breast cancer survivors.

Phase Two Findings and Interpretation

Based on the findings from Phase One, an interview protocol was developed to gain the perspectives of healthcare providers' who had experience working directly with breast cancer survivors. Phase Two examined the direct and supportive-care healthcare providers' perceptions of the challenges and unmet needs of breast cancer survivors in Alaska. In addition, providers were asked to identify feasible ways to satisfy the unmet needs and improve services for Alaskan breast cancer survivors. Following is a summary of the most important and salient findings from Phase Two.

Breast cancer service-related barriers. Healthcare providers identified key challenges related to service access. These challenges included lack of access to available and needed services along with shortages of key professionals. Provider shortages were especially predominant in rural Alaska. Regardless of geography, however, significant need was revealed for more ancillary providers (such as patient

navigators, psychologists, and physical therapists) who have experience working with breast cancer survivors.

Other service-related barriers were logistical, often related to Alaska's vast geographical makeup and diverse population. Barriers were identified in relation to financial, health insurance, housing, travel, and employment issues. Numerous providers highlighted the challenges experienced by individuals who have financial limitations or lack health insurance. Providers discussed the difficulties that emerge for some women who have to travel to receive treatment services or who need to relocate for extended periods of time while receiving treatment (i.e., radiation therapy). Lastly, a number of healthcare providers shared employment issues they have heard about from survivors on countless occasions. Many survivors are faced with having to work to maintain health insurance, despite often feeling too ill to work.

Providers also highlighted information deficits as service-related barriers. Perhaps one of the most important concerns emerged over the perception that women often lack knowledge and understanding about their disease and about the implications of various treatments. Providers acknowledged they often have to repeat information, likely due at least in part to survivors not understanding information when it is initially presented. Other providers expressed the need to repeat information as a way to try to assure survivors they are receiving all needed information. A lack of service awareness was recognized by numerous providers, with patients reportedly not being aware of the variety of direct and supportive care services available to them in urban areas of Alaska. Lastly, providers shared the belief that women are not truly informed about side effects of various treatments (e.g., cognitive deficits following chemotherapy) and the immediate and long-term impacts on their quality of life. These providers called in question whether breast cancer patients are always truly able to give informed consent for their treatment choices.

Breast cancer service, system, and training gaps. Healthcare providers identified several service, system, and training gaps. Almost all providers described oncology care in Alaska as fragmented and in need of improved care coordination.

Providers highlighted the period when survivors are transitioning to long-term care as a difficult time when survivors may feel abandoned by their "cancer care team." They pointed out that this transition affects not only survivors, but their entire family unit. Informants further stressed that enhanced communication between providers, specifically oncology providers and primary care providers, could ease this transition period for patients. Training and education gaps were noted across disciplines. Interviewees emphasized that healthcare providers need to increase awareness of available services, as well as the specialty services and knowledge of their colleagues. Interviewees called for improved communication with patients about treatment side effects. They indicated breast cancer survivors must be better prepared for what to expect during and following treatment to allow them to develop coping strategies. Two areas highlighted in this context were related to talking to patients about sexual and psychological issues during and following treatment.

Training needs also emerged in the context of work places and human resource offices. These services must become knowledgeable about side effects of cancer treatment and must develop more realistic expectations for employees who return to work during and following cancer treatment.

Healthcare providers' roles in breast cancer care. Healthcare providers reflected on what the optimal role of providers should be when working with breast cancer survivors. Across disciplines, key informants expressed a need to improve awareness of services available to breast cancer survivors outside of conventional medical treatment. In fact, multiple key informants expressed a need for direct cancer service providers to increase referrals to complementary and alternative services. They revealed the belief that integrated cancer care was an ideal that was yet far from reach.

Interviewees also expressed that it is the healthcare provider who is responsible for assuring adequate communication with survivors, clarifying that given the stress experienced by patients, they cannot be expected to be the ones who are proactive about seeking out information and detail. Topics of importance were related to sexual side effects and screening for anxiety and depression. Despite holding providers accountable

for proactive communication, interviewees also stressed that women needed to be encouraged to become advocates for their health and wellbeing.

Breast cancer service, system, and care structure improvements. Participants identified several ways to address the needs of breast cancer survivors in Alaska. As noted above, informants commented that they find themselves having to repeat information with their cancer patients. They concluded one way to help survivors retain needed information is to offer survivors the option of recording their office visits. One provider, a breast cancer survivor, found this to be a helpful technique for several reasons. It allowed her to share information with family members; it helped family members develop a better understanding of what the patient's cancer care would entail; and it boosted her own memory and ability to re-expose herself to the information. Several providers mentioned efforts in the past toward developing a survivorship clinic· where cancer patients could receive all care and follow-up under one roof. Unfortunately, the notion of a survivorship clinic was not embraced by all parties who were needed to participate. Nevertheless, the idea of working toward developing a survivorship breast clinic was mentioned by the current group of participants as a potentially beneficial way to unfragment care and decrease travel time and effort. Informants also identified the need for a breast cancer navigator who works solely with breast cancer patients. Several providers from one of the main hospitals in Alaska proudly stated they were in the midst of hiring a breast cancer navigator who would work to meet the needs of the hospital's breast cancer survivors. Creating additional positions for breast cancer navigators across all major treatment facilities in Alaska was acknowledged as an ongoing goal and need.

Interviewees acknowledged several system changes that would benefit breast cancer survivors in Alaska. The first area identified was the need to improve coordinated care for patients. Currently care is fragmented for several reasons. First, there are a large number of private entities who offer direct cancer care. These entities do not necessarily attempt to coordinate among themselves. Second, patients tend to go where their insurance or other medical coverage will pay for their treatment. This may result in

uncoordinated care in that the various providers are not used to working with each other. Improvements in coordinated care were perceived as an important strategy to improve overall services and care.

One way of improving coordinated care between treating oncologists and primary care providers (PCP) is a survivorship care plan for each patient who completes treatment and is transferred back to a PCP. The majority of key informants confirmed formal survivorship care plans were crucial to coordinated care, yet not currently commonly used in Alaska. The Alaska Comprehensive Cancer Partnership was identified by informants as having placed coordinated care on their action agenda for fiscal year 2011-2012. Another means to improve care coordination and meet survivors' needs is the patient-centered medical home. Such a medical home for oncology survivors would allow patients to have their direct medical needs met while concurrently addressing emerging psychosocial and other needs. Several US states have begun to implement the concept of patient-centered medical home to deliver oncology services (Sprandio, 2010).

Lastly, informants spoke to the need to improve and make available alternative and complementary services for breast cancer survivors. Numerous interviewees identified oncology rehabilitation being extremely beneficial to patients and long-term survivors. However, currently survivors have reported only being able to take advantage of these services if they receive oncology care in Anchorage. Thus, interviewees stressed the importance of expanding rehabilitation services to other areas in Alaska. Although numerous supportive care services are available to patients and survivors, informants called for more. They mentioned in particular needs for more support groups, services for families, and professionals who have experience working with breast cancer patients and survivors. Interestingly, key informants stressed they may not be familiar with all the services currently offered in the primary areas where survivors receive cancer treatment (namely, Anchorage, Fairbanks, and Mat-Valley). This lack of knowledge even on the part of the experts who were interviewed only serves to speak to the need for continual efforts to disperse information about supportive care services available to cancer survivors in Alaska.

Rural breast cancer survivors: challenges and system improvements

Rural breast cancer survivors are challenged with a host of additional needs due to vast distances they often have to travel to receive services. Challenges identified by providers included logistical barriers, such as arranging travel accommodations and making it to medical appointments depending on the changes in the weather. Financial barriers were identified as a large challenge due to the high cost of living in rural areas of Alaska. Obtaining access to services was a continual challenge identified by participants. The press for more physicians and other healthcare providers was also identified, with interviewees indicating the state of Alaska is constantly trying to address this issue through reward programs and other incentives. The concept of cultural barriers was acknowledged as the reason some rural patients may not seek medical care or may find it challenging and intimidating to navigate the medical system successfully.

Several providers identified the need to incorporate telemedicine services into rural areas to help providers communicate successfully with patients in remote areas. Telemedicine was also identified as a means for providers to communicate and consult with specialists outside the immediate geographic area. Providers who are also breast cancer survivors, living in rural Alaska, identified the need for more support groups that reach into rural areas. One supportive event that was identified as occurring in rural areas was survivorship dinners which allow cancer survivors to gather with their families to show support for one another and share their stories. These survivorship dinners were identified as a helpful way for rural cancer survivors to feel more supported within their community and connected to each other.

Conclusions

Breast cancer survivors and healthcare providers offered unique perspectives on the needs of breast cancer survivors in Alaska. Breast cancer survivors identified several areas of care that need improvement, namely care coordination, treatment for side effects, and communication with direct care providers. Young breast cancer survivors are challenged with different obstacles and issues when compared to their older counterparts. In addition, survivorship phase was shown to be a key factor in managing psychological

wellbeing and side effects. For all patients, the preferred method of obtaining information about treatment and services was through consultation with their direct healthcare providers.

The wide range of healthcare providers represented in this study possessed a solid knowledge base of some of the key challenges breast cancer survivors face living in Alaska. They identified key barriers and service gaps to meeting breast cancer survivors' needs. They also discussed areas for improvement that have the potential to lead to more comprehensive care for Alaskan breast cancer survivors. Drawing on the information shared by breast cancer survivors and key experts in care provision, the next chapter will present a set of recommendations aimed at improving the care available to Alaskan breast cancer survivors.

Limitations of Phase One and Phase Two

The recommendations that will be offered in the next chapter were developed with careful consideration of a number of limitations that were inherent in this study. With regard to Phase One, the sample obtained was disproportionately comprised of Caucasian females in their mid-fifties, college graduates, middle-to-upper class women, and urban residents. The sample was not an optimal representation of breast cancer survivors in general and in particular of breast cancer patients in rural areas, with low income, or with health insurance constraints. The sample obtained for the survey differed in important ways as compared to state averages (U.S. Census Bureau, 2011). More specifically, over twice as many women in the sample (63.2%) completed at least a bachelor's degree, as compared with the state average of 26.5%; the median household. income of $70,000 to $79,000 was higher than the state average of $66,712; and American Indian and Alaska Native women comprised only 7.8% of the sample, as compared to 14.8% in the state as a whole (U.S. Census Bureau, 2011).

Obtaining a more diverse sample representative of women in Alaska may have offered further information about unmet needs of Alaskan breast cancer survivors. One population in particular, Alaska Native women, was woefully underrepresented in this

sample. Unfortunately, due to the archival nature of the data, the sample obtained could not be modified for the purpose of this study.

The survey used to gather the archival data from this sample of women was developed specifically for use with breast cancer survivors in Alaska. Therefore, the results may not be valid for survivors residing outside of Alaska in states with different geographical makeup and alternative systems of medical care. It is the first survey of its kind to assess the needs of Alaskan women; its psychometric properties have not been explored. With the development of a new measure without the establishment of psychometric properties, validity and reliability of the measure are unknown. Future research to establish the reliability and validity of the ACBCNA would help provide confidence in the results from this initial evaluation. In addition, the ABCNA survey simply assessed self-reported attitudes and behaviors and responses may have been confounded by social desirability biases.

With regard to data analyses in Phase One, statistical power was an issue due to the low numbers of participants in several of the subgroups. Using archival data inhibited the ability to increase the overall sample size to gain more statistical power. Further, among the independent variables, access to treatment services and survivorship phase, the sample was also not evenly distributed across groups. Without approximately even distribution of a sample within groups, assumptions of normality and homogeneity can be violated. In addition, when the categories are unevenly distributed, it is challenging to detect significant differences due to compromised statistical power.

For Analyses One (treatments and services not received) and Two (additional information about treatment and services), the dependent variables were dichotomous (received/not received; wanted information/did not want information) and called for analyzing sets of categorical variables. This limited the type of statistical analyses that could be performed to determine if relationships existed between variables. For Analyses One and Two, multiple comparisons using Chi Square analyses were performed with no adjusted alpha levels, leading to a potential increase in Type I error. Using chi-square analyses to examine the relationships between categorical variables has its limitations.

The chi-square test provides limited information about the strength of the relationship or its substantive significance in the population. It is also sensitive to sample size. When effect sizes were examined, they were small for the significant finding, indicating only a small percentage of the overall variance was accounted for. The significant findings from Analyses One and Two should thus be interpreted with caution.

For Analyses Three (Physical Wellbeing), Four (Psychological Wellbeing), and Five (Daily Living Challenges), the dependent variables were continuous in nature (4-point Likert scale) and allowed for exploration of differences between multiple dependent variables. One of the draw backs of calculating multiple ANOVAs is in the need to control for familywise error rate. To control for Type I error, Bonferroni correction utilized; however, this is a conservative test that may obscure significant findings. Additionally, the effect sizes for all statistically significant variables were small, indicating only a small percent of the overall variance was accounted for.

Limitations also existed in Phase Two of this study. To counterbalance the overrepresentation of urban breast cancer survivors in Phase One, an effort was made to recruit healthcare providers with experience working with rural breast cancer survivors. This effort was marginally successful as a majority of providers who were willing and available to participate were located within the Anchorage area. The kinds of informational and support networks that helped to locate study participants in more urban settings were not fruitful in the rural context. Some rural providers were more isolated and less responsive to requests despite efforts made. The study would have benefited from gaining the perspectives of more providers who live in rural Alaska and service rural breast cancer survivors. One sample-set of providers that was particularly difficult to obtain was direct oncology providers (i.e., breast surgeons, radiation oncologist, and medical oncologists). Not only were there a lower number of these rural providers in the recruitment pool, they were less likely to be responsive to interview requests and willing to participate. This may suggest the need for an alternative research design, perhaps including more extensive ethnographic fieldwork, if further information is needed on rural settings. Additional challenges related to recruitment include the time of year the

interviews were conducted (i.e., December and January) and conducting the interviews over a short period of time (six weeks) providing a limited window of availability during the holiday season.

Chapter 7 Recommendations for Meeting the Needs of Breast Cancer Survivors in Alaska

Phase Three of this study combined information from Phases One and Two with a literature review to develop a set of recommendations designed for healthcare providers, hospital groups, and key community stakeholders in Alaska. Recommendations are organized into the following five areas

1. Recommendations to address service gaps and improve communication;
2. Recommendations to address psychosocial needs;
3. Recommendations to address needs specific to rural breast cancer survivors;
4. Recommendations to improve coordination of care; and
5. Recommendations to implement survivorship care plan(s) within Alaska's healthcare system.

Recommendations for Addressing Service Gaps and Improving Communication

Effective patient-provider communication. Based on study findings, good communication with providers was found to be particularly important for patients during the time of diagnosis and when determining optimal course of treatment. Kahan and colleagues (2006) found most patients, including those with cancer, wanted more information from their physicians. Participants in the study were also dissatisfied with the amount of information provided and when information was disseminated. This finding aligns with research that has shown clinicians often have a limited understanding of patients' information needs, knowledge, and concerns. They often do not provide the type or amount of information patients need and fail to communicate in an understandable manner (Epstein & Street, 2007; Kahan, Varga, Dudas, Nyari, & Thurzo, 2006).

Epstein and Street (2007) identified the following six components of effective patient-clinician communication, as stated in The National Cancer Institute (NCI) report, *Patient-Centered Communication in Cancer Care*:

1) fostering healing relationships
2) exchanging information

3) responding to emotions
4) managing uncertainty
5) making decisions
6) enabling patient self-management

Based on these recommendations, it is important for healthcare providers to communicate diagnosis and treatment options to their patients. The Center for Behavioral Health Research and Services (CBHRS) identified the following recommendation to improve communication with breast cancer survivors and their Alaskan providers: "Continue to explore and develop methods of communication to keep survivors in Alaska informed of advances in breast cancer care, the resources and support available in their area, and opportunities to connect with other breast cancer survivors" (CBHRS, 2010, p. 12).

Use of technology to improve communication. Interviewees acknowledged they frequently spend time repeating information previously covered and identified the benefit of recording office visits and feedback sessions with surgeons, radiation specialists, and medical oncologists. It is recommended patients be encouraged to bring or are supplied with recording devices to use during medical appointments as a way to gather and retain pertinent treatment information. Such action should help decrease the number of times providers have to repeat information to patients to assure retention and understanding. Cegala, McClure, Marinelli, and Post (2000) found interventions to improve patient participation in care, such as utilizing audio-taping of visits, were linked with increased quantity and quality of patient involvement in treatment decisions.

Improved referrals to and communication among ancillary service providers. Direct and support services providers should be encouraged to communicate with one another to gain knowledge of others' professional services and increase referrals for patients. CBHRS (2010) identified a similar need and made the following recommendations:

- *Consider resources from a variety of sources such as written or online informational material, support programs, and financial assistance.*

- *Become informed about the resources available in their area that may support breast cancer patients. Breast cancer survivors preferred to hear information one-on-one from providers over other forms of information delivery.* (pp. 11-12).

In addition, the *Alaska Comprehensive Control Plan 2005-2010* (developed by DHSS, 2006) identified the need to support annual continuing education about best practices in cancer care for all providers who service cancer patients. When providers are familiar with cancer-related resources and different types of providers, improvement in referrals to ancillary services should result.

Program development and training.

Seek funding for survivors. One of the key barriers identified by healthcare providers was related to financial constraints. A continual need exists to find financial resources in Alaska to help pay for the cost of treatment and logistical challenges (i.e., arranging travel and housing accommodations). Although some grant programs are available to qualified individuals, patients often do not qualify, making it challenging to locate financial resources. The needs assessment conducted by CBHRS (2010) revealed similar findings and provided the following recommendation:

> *Secure funding to develop programs and policies to support women with breast cancer who are struggling financially due to difficulty maintaining employment while undergoing treatment and recovery, paying for the high cost of treatments, or failing to receive adequate health insurance coverage (p. 12).*

Train employers. Past research has shown breast cancer survivors in various types of jobs have experienced job loss, demotion, unwanted changes in tasks, problems with their employer and coworkers, personal changes in attitudes toward work and diminished physical capacity (Maunsell, Brisson, Dubois, Lauzier, & Fraser, 1999). With regard to employment, a continual need exists to educate employers and human resource departments on ways to interact and support employees and colleagues who have cancer. Employers need to be trained about realistic physical and psychological expectations from employees during and following cancer treatment. Thorsness (2011)

identified the need to educate employers about how to support cancer survivors in the workplace as part of the Alaska Comprehensive Care Partnership 2011-2012 survivorship agenda.

Train oncology office personnel. Interviewees identified the need for support staff to be responsive to breast cancer patients' concerns, regardless of how insignificant they may seem. They acknowledged a portion of individuals who work directly with cancer patients are appropriately responsive and sensitive to patients' needs; however, other care providers need additional training to be more compassionate and understanding. Receiving and dealing with a diagnosis of cancer can create a fragile and vulnerable period of time for patients and their support systems. At the very least, individuals who have direct encounters with cancer survivors need to learn to become sensitive to their own needs and emotions. Training is needed for oncology office support staff concerning communication with cancer survivors and their families. They need to raise awareness about key experiences that will likely emerge during the course of treatment and into survivorship.

Support established programs. A clear need exists to support already established programs that are serving breast cancer survivors in Alaska. The American Cancer Society (www.cancer.org) sponsors Reach to Recovery, Road to Recovery, I Can Cope – Nutrition, and Look Good . . . Feel Better. These programs are offered in the Anchorage area, but efforts must be made to extend such services to outlying areas of Alaska. In addition, the Alaska Cancer Care Alliance, (www.alaskacanceralliance.org) a relatively new organization (established in 2009), strives to bring together patients, providers, agencies, and programs to help patients and their families identify and access resources, supports, and strengths to manage cancer care. Beneficial programs are available to cancer patients and survivors in Alaska; however, a need remains to support these programs and assure their sustainability and penetration into regions of Alaska beyond Anchorage.

Additional programs needed. Currently no formalized programs exist that deliver supportive care services based on age at diagnosis in Alaska. Younger and older

breast cancer patients face a host of unique challenges depending on their age at diagnosis. As suggested by this study, younger women are faced with a specific set of challenges related to breast cancer treatment (i.e., difficulty with their relationships, concerns with their appearance, and issues related to sexuality). The development of an educational program supporting young breast cancer survivors would be beneficial to women in Alaska. The program could model itself after the Dana-Farber Cancer Institute (2011) Young Women with Breast Cancer Program and might offer support and information in the following areas:

- Fertility and reproductive options
- Sexual health and body image issues
- Genetic counseling
- Psychosocial needs
- Management of menopausal symptoms
- Survivorship
- Research opportunities

CBHRS (2010) identified the need to offer additional programs for women newly diagnosed with breast cancer. Such services could be tailored to two separate groups, individuals diagnosed in early stages and those diagnosed in later stages of breast cancer. An educational program could offer women newly diagnosed with information and support needed to understand the implications of their diagnosis, make treatment decisions, and plan for the future. CBHRS suggested the following services be included:

- *Treatment options and preparing for potential physical side effects*
- *Emotional and psychological effects of having breast cancer*
- *A chance to speak with and hear from other survivors of breast cancer*
- *Information about local resources for financial assistance, travel, emotional support, household assistance, and support groups*
- *Reconstructive surgery and breast prostheses*
- *Nutrition and healthy living (p. 12).*

Recommendations for Rural Breast Cancer Survivors and Providers

Meeting logistical barriers. Rural breast cancer survivors face a host of challenges in addition to common survivorship issues. They are diagnosed later in the process of the disease, presumably due to lack of access to screening and diagnosis. Once diagnosed, they are faced with readjusting to returning to their community and way of life after being gone for an extended period of time for treatment. They often have difficulty keeping appointments for treatment and follow-up care due to logistics and financial cost involved in travel. Creating availability of breast cancer navigators who are responsible for supporting rural breast cancer survivors would be ideal. Such navigators could be responsible for reminding women of appointments and helping them arrange necessary travel accommodations. In addition, navigators could provide periodic follow-up to see how patients are adjusting to returning to their rural location, offering additional support as necessary. CBHRS (2010) made the following recommendations to improve earlier detection and address barriers for rural breast cancer survivors:

> *Advocate for methods to decrease the number of late stage breast cancer diagnoses for women living in rural and remote areas of Alaska through methods such as reducing travel and financial barriers to receiving a diagnosis, providing further education to women living in rural areas, and increasing resources to allow women to be diagnosed closer to home (p. 12).*

Supportive care services. Rural breast cancer survivors often feel isolated and unsupported depending on availability of other community members who have experienced the disease. Not surprisingly, interviewees identified a need to increase supportive care services in rural areas of Alaska. As a way to provide support for fellow cancer survivors and bring community members together, they suggested the organization of more survivorship dinners. Survivorship dinners are seen as positive events where cancer survivors can gather and feel honored and supported by their communities. Such dinners may provide platforms for survivors to share their "cancer story." More formal support groups were identified as yet another important added resource for breast cancer survivors in rural areas of Alaska. Support groups can offer a

place for women to come together to share concerns and feel supported by individuals with similar experiences. Breast cancer survivors who have participated in support groups were found to have significantly higher levels of social and overall quality of life (Michalec, 2005).

Provider recruitment. Due to a lack of providers in rural areas, it becomes crucial to recruit more physicians and direct medical providers interested in living and working in rural Alaska. Recruiting providers with an interest in caring for cancer survivors is a specific need. The State of Alaska has made efforts to address the inadequate availability of such medical and allied health professionals in the state. These efforts have included implementing recruitment programs for medical, allied health, and behavioral health providers; developing training programs tailored to increase providers' knowledge and skills about rural service provisions; and creating educational programs with the purpose of training Alaskan residents to fill the void in these health professions (Alaska Physician Supply Task Force, 2006; WICHE Mental Health Program, 2004). In agreement, the *Alaska Comprehensive Cancer Control Plan 2005-2010* (DHSS, 2006) and the *Comprehensive Cancer Plan for the Alaska Tribal Health System 2005-2010* (ANTHC, 2006) identified similar needs and made recommendations to recruit and retain oncology providers for the state of Alaska.

Telemedicine. Telemedicine has the potential to facilitate delivery of cancer-related health services in rural areas of Alaska. Under the right circumstances, telemedicine could be used for patients to follow-up with oncologists, for rural healthcare providers to consult with oncology specialists about appropriate follow-up care, and to screen for psychosocial needs of survivors as they reenter and readjust to their communities. Efforts have been made to begin implementation of telemedicine services in rural areas of Alaska (Hofstetter, Kokesh, Ferguson, & Hood, 2010; Hudson, 2005); however, these services are not specialized in oncology. One newly published study (Kroenke et al., 2010) found using telemedicine coupled with automated symptom monitoring resulted in improved pain and depression outcomes for cancer patients receiving care across urban and rural oncology practices. Efforts should be made to

incorporate telemedicine as a tool to provide cancer-related follow-up services to rural cancer survivors and provide an avenue for consultation with rural healthcare providers.

Recommendations to Address Psychosocial Needs of Breast Cancer Survivors

National standards and recommendations. Quantitative and qualitative data collected for this study call for strategies to address the psychosocial needs of breast cancer survivors in Alaska, an ongoing need that has also been identified nationally. To address psychosocial needs of breast cancer survivors, the National Institutes of Health tasked the Institute of Medicine (IOM) with creating a committee to conduct a study of the delivery of diverse psychosocial services necessary for cancer patients and their families in community settings. The committee produced a report, *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs* (IOM, 2007) that described barriers to accessing psychosocial services and improved ways for providing such services. The committee analyzed the capacity of current mental health and cancer treatment systems to deliver such care, delineated associated resource and training requirements, and offered recommendations and action plans for overcoming identified barriers. Through its report, the committee identified the following five components for effective delivery of psychosocial health services (IOM, 2007):

1. *identify psychosocial health needs*
2. *link patients and families to needed psychosocial services*
3. *support patients and families in managing the illness*
4. *coordinate psychosocial and biomedical health care*
5. *follow-up on care delivery to monitor the effectiveness of services and make modifications if needed*

Routine implementation of these recommendations is underway by some oncology providers in different settings with varying levels of resources. However, many patients do not have the benefit of these interventions; thus, steps are needed for widespread implementation. Based on the current findings, providers must begin to consider how they can address the psychosocial and formal services needs of their patients. Table 42 provides an overview of the needs and services identified (IOM, 2007,

p. 8) as a means of offering local care providers ideas about how to begin to attend to the psychosocial needs of Alaska breast cancer survivors.

Table 42

Psychosocial Needs and Formal Services to Address Them

Psychosocial Need	Health Services
Information about illness, treatments, health, and services	• Provision of information (e.g., on illness treatments, effects on health, and psychosocial services, and helping patients/families understand and use the information)
Help in coping with emotions accompanying illness and treatment	• Peer support programs • Counseling/psychotherapy for individuals or group • Pharmacological management of mental symptoms
Help in managing illness	• Comprehensive illness self-management / self-care programs
Assistance in changing behaviors to minimize impact of disease	• Behavioral/ health promotion interventions such as o Provider assessment/ monitoring of health behaviors (e.g., smoking, exercise) o Brief physician counseling o Patient education (e.g., in cancer related health risk and risk reduction measures)
Material and logistical resources, such as transportation	• Provision of resources
Help in managing disruptions in work, school, and family life	• Family and caregiver education • Assistance with activities of daily living (ADLs), instrumental ADLs, chores • Legal protections and services (e.g., under Americans with Disabilities Act & Family Medical Leave Act) • Cognitive testing and educational assistance
Financial advice and/or assistance	• Financial planning/counseling including management of day-to-day activities such as bill paying • Insurance (e.g., health, disability) counseling • Eligibility assessment / counseling for other benefits (e.g., Supplemental Security Income, Social Security Disability Income) • Supplemental financial grants

Screening for emotional needs. As discussed above, although medical needs of cancer patients tend to be addressed adequately, psychosocial and emotional needs of survivors are often overlooked. Interviewees highlighted the crucial need to better address emotional needs of breast cancer patients. They acknowledged time constraint as a hindrance that impedes providers from addressing patients' psychosocial needs. Several screening tools and in-depth assessment instruments are available for use by healthcare providers to assess psychosocial health needs of patients. Many of these

screening tools are brief and can be self-administered by the patient, possibly completed while waiting for medical appointments to begin. For example, screening tools (e.g., the Brief Symptom Inventory [BSI]; Derogatis, 2006) can measure depression, anxiety, and overall psychological distress levels while requiring only approximately five minutes of administration time. The BSI's reliability, validity, sensitivity, and specificity have been documented in samples involving more than 1,500 cancer patients with more than 35 different cancer diagnoses (Zabora et al., 2001). To better serve breast cancer patients in Alaska, it would be beneficial for local oncology offices to begin screening for patients' psychosocial needs, perhaps utilizing the BSI, on a regular basis.

Recommendations to Improve Care Coordination

A common thread identified by both breast cancer survivors and healthcare providers is the lack of coordinated cancer care in Alaska. Women and providers identified the need for better care coordination. CBHRS (2010) made the following recommendations to address this issue:

- *Each hospital should work towards developing a more coordinated system of care for breast cancer patients which includes the following suggested components:*
  - *Patient navigator or case manager to assist patients with questions, appointment scheduling, insurance, and linkages to local resources*
  - *Breast cancer treatments, services, and information housed in one facility*
  - *A team decision making approach to treatment and services*
  - *Strong communication between treatment providers and between providers and patients (p. 12).*

Increase collaborative care during active cancer treatment.

Multidisciplinary care. One way to improve care coordination is using a multidisciplinary approach. It is important for healthcare providers to understand the benefits of utilizing a multidisciplinary approach when treating breast cancer patients and survivors and to be educated about effective strategies for improving referrals and coordination of care. A multidisciplinary approach incorporates various treatment

modalities to address the wide range of physical and psychological issues associated with breast cancer, including, but not limited to, physical therapists, nutritionists, naturopathic doctors, genetic counselors, patient navigators, social workers and psychologists (Kim & Toge, 2004).

Distress management. As part of multidisciplinary care, the ability to identify and manage distress symptoms during the course of treatment is of importance when providing wrap-around services to breast cancer survivors. The National Comprehensive Cancer Network ([NCCN], 2010b) offered clinical practice guidelines for addressing the management of distress. They recommended that symptoms of distress be screened for throughout the course of treatment and handled by a multidisciplinary team equipped to address the medical and psychosocial needs of breast cancer patients. NCCN's distress guidelines include three primary components:

1) screening of all patients at their initial visit, at appropriate intervals, and as clinically indicated to determine the level and nature of distress;
2) further evaluation, triage, and referral of patient with significant distress to appropriate resources for care; and
3) education of patients and their families about distress and its management (NCCN, 2010b).

Collaborative care after transitioning to primary care.

Collaborative care model. When cancer treatment is completed, the survivors are faced with transitioning from their oncologists' care back to their primary care provider. To deliver comprehensive services, survivors need to be offered healthcare from a collaborative model of care equipped to address their numerous issues following cancer treatment. One model of collaborative care, developed by Katon (2003), examined the involvement of mental health specialists in a primary care setting. This approach employs the following four components:

- a negotiated definition of the clinical problem in terms that both patient and physician understand;

- joint development of a care plan with goals, targets, and implementation strategies;
- provision of support for self-management training and cognitive and behavioral change; and
- active sustained follow-up using visits, phone calls, email, and web-based monitoring and decision-support systems (Katon, 2003).

Initial studies found patients receiving such integrated care showed significant improvement in depressive symptoms over a 12-month period when compared to patients who received usual primary care (Katon et al., 1995). In a pilot study, collaborative care has been shown to be effective in treating low-income Latina women with cancer (Dwight-Johnson, Ell, & Lee, 2005).

Patient-centered medical homes. To make primary care a more attractive career choice and facilitate comprehensive quality medical care, efforts are underway to revamp primary care services. One model currently receiving a substantial amount of attention is the patient-centered medical home. Designed to be a more inclusive, holistic approach to primary medical care, this model uses advanced practice nurses and other support providers to offer care and education for patients. The model relies extensively on electronic medical records to bridge patient care and knowledge gaps, and to enable healthcare professionals to apply current medical guidelines and information in real-time at the point of service (Lee, Bodenheimer, Goroll, Starfield, & Treadway, 2008). Such a model could be adapted to serve breast cancer survivors in primary care settings.

Group visits. Another way breast cancer survivors could be cared for by primary care providers in a supportive environment is through the use of group visits. A group visit, also known as a shared medical appointment, includes a medical examination along with group education. During a group visit, multiple patients are seen together for follow-up or routine care. According to the American Academy of Family Physicians, such visits provide patients with a secure, interactive setting with improved access to physicians; the benefit of counseling or consultation with additional healthcare providers (e.g., behaviorists, nutritionists, or health educators); and the opportunity to share

experiences and advice with other patients (Masley, Sokoloff, & Hawes, 2000). It is important to provide training and education to physicians regarding the use of group visit paradigms to provide intensive and comprehensive care for breast cancer survivors. Group visits have been shown to improve patient outcomes through increased patient-physician interaction and communication, increased opportunity for answering patient questions and addressing health concerns, and patient empowerment around health behavior change (Masley et al., 2000).

Recommendations Related to Survivorship Care Plans

National recommendation to implement survivorship care plans. Based on responses from healthcare providers in Alaska, no formal survivorship care plan is currently in place to offer breast cancer patients following treatment completion. One of the reasons survivorship care plans are not currently in use is the significant challenge of implementation. As a follow-up to the 2006 IOM report, the National Cancer Institute, National Coalition of Cancer Survivors, and the Lance Armstrong Foundation supported a workshop on implementing survivorship care planning and conducted a focus group analysis of ways care plans could improve the quality of survivorship care (Hewitt, Bamundo, Day, & Harvey, 2007; IOM, 2006;). This qualitative research revealed enthusiasm among survivors and receptiveness among primary care providers, who welcomed the plan, thus acknowledging the importance in their post-treatment role. Nurses emphasized the need to improve survivor care and acknowledged they could play an active role in creating and implementing survivorship care plans. Oncologists, although articulating support for the concept, were not inclined to complete survivorship care plans because of other time-intensive reporting and communication requirements. Oncologists' attitudes and support must be addressed for care plans to become reality.

Survivorship care plans are meant to be dynamic documents that change with the circumstances of individual patients and with the growth of knowledge and guidelines in specific treatment areas. The most important aspects of survivorship plans are open communication across the spectrum of survivors' needs and concerns and clarity for patients and providers. The new paradigm, which encourages successful transition from

direct cancer care to healthy survivorship, must become an integral part of oncologists' education and practice for maximum success. Care plans must include shared educational opportunities and training, guidelines, and formalized action plans, with the inclusion of primary care physicians as part of a multidisciplinary team.

Components of survivorship care plans. In 2006, the Institute of Medicine issued a report recommending every cancer patient receive an individualized survivorship care plan, including guidelines for monitoring and maintaining health. The following recommendation was made by the IOM 2006 report:

> *Patients completing primary treatment should be provided with a comprehensive care summary and follow-up plan that is clearly and effectively explained. This Survivorship Care Plan" should be written by the principal providers(s) that coordinated oncology treatment. This service should be reimbursed by third-party payers of health care (p. 151).*

When discussing the ability to implement such a paradigm shift in cancer treatment, Earle, Schrag, Woolf, and Ganz (2007) acknowledged changing the culture of medical record documentations will be challenging and can only be successful if survivorship care plans are linked to reimbursement. The absence of such a link may explain why to date there is no evidence of a formal survivorship care plan in Alaska despite the recommendations from the IOM more than five years ago. The Institute of Medicine (2006) proposed two primary components of a survivorship care plan, namely a Record of Care and Standards of Care, as shown in Table 43.

Table 43

Recommended Components of Survivorship Care Plan

Record of Care	Standards of Care
Upon discharge from cancer treatment, including treatment of recurrences, every patient should be given a record of all care received and important disease characteristics. This should include, at a minimum:	Upon discharge from cancer treatment, every patient and their primary health care provider should receive a written follow-up care plan incorporating available evidence-based standards of care. This should include, at a minimum:
• Diagnostic tests performed and results. • Tumor characteristics (e.g., site(s), stage and grade, hormonal status, marker information). • Dates of treatment initiation and completion. • Surgery, chemotherapy, radiotherapy, transplant, hormonal therapy, gene or other therapies provided, including agents used, treatment regimen, total dosage, identifying number and title of clinical trials (if any), indicators of treatment response, and toxicities experienced during treatment. • Psychosocial, nutritional, and other supportive services provided. • Full contact information on treating institutions and key individual providers. • Identification of a key point of contact and coordinator of continuing care.	• The likely course of recovery from treatment toxicities, as well as need for ongoing health maintenance/adjuvant therapy • A description of recommended cancer screening and other periodic testing and examinations, and the schedule on which they should be performed (and who should provide them). • Information on possible late and long-term effects of treatment and symptoms of such effects. • Information on possible signs of recurrence and second tumors. • Information on the possible effects of cancer on marital/partner relationship, sexual functioning, work, and parenting, and the potential future need for psychosocial support. • Information on the potential insurance, employment, and financial consequences of cancer and, as necessary, referral to counseling, legal aid, and financial assistance. • Specific recommendations for healthy behaviors (e.g., diet, exercise, healthy weight, sunscreen use, virus protection, smoking cessation, osteoporosis prevention). • When appropriate, recommendations that first degree relatives be informed about their increased risk and the need for cancer screening (e.g., breast cancer, colorectal cancer, prostate cancer). • As appropriate, information on genetic counseling and testing to identify high risk individuals who could benefit from more comprehensive cancer surveillance, chemoprevention, or risk reducing surgery. • As appropriate, information on known effective chemoprevention strategies for secondary prevention (e.g. Tamoxifen in women at high risk for breast cancer; aspirin for colorectal cancer prevention). • Referrals to specific follow-up care providers, support groups, and/or the patient's primary care provider. • A listing of cancer-related resources and information (Internet-based sources and telephone listings for major cancer support organizations).

Recommended survivorship care plans for pilot testing in Alaska. The implementation of survivorship care plans might become more feasible and widespread if standardized forms (ideally in electronic format) were freely available. Efforts have been made to create templates of survivorship care plans that could be utilized for Alaskan cancer survivors. Horning (2008) identified a treatment summary and survivorship care plan that was created through the American Society of Clinical Oncology (ASCO). These forms can be found through two websites www.asco.org and www.plwc.org and can be modified to fit individual practitioners' needs.

Journey Forward (www.journeyforward.org) offers an electronic survivorship care plan program that is free to download. The program facilitates a means for survivors and their care providers to work collaboratively following active treatment. The survivorship care plan offered through Journey Forward is viewed as a coordinated post-treatment plan for the survivor's oncology team, primary care physician, and other health care professionals. The oncologist creates a summary of the survivor's treatment and includes directions for future care. A typical survivorship care plan includes the following components:

1. patient diagnosis and treatment summary;
2. best schedule for follow-up tests;
3. information on the latent and long-term effects of cancer treatment;
4. list of possible symptoms; and
5. list of support resources (Journey Forward, 2011).

An example of a breast cancer survivorship care plan Journey Forward offers is shown in Appendix I. Patient demand, use of electronic health records, and reimbursement from insurance companies will facilitate widespread adoption of survivorship care plans, including implementation in Alaska.

Future Research Considerations

The current study aimed to identify the needs of breast cancer survivors specific to the state of Alaska. Based on quantitative findings, more research is needed to further tease out specific needs as they relate to breast cancer survivors' age at diagnosis and

survivorship phase. Although other researchers have assessed some of these needs (CBHRS, 2010; Mayer & Grober, 2006; Stephens et al., 2008), further research in these areas utilizing Alaskan breast cancer survivors is warranted. When conducting future research with breast cancer survivors in Alaska, the ABCNA needs to undergo psychometric studies to determine is reliability and validity. Through such studies, increased confidence may be given to the findings of the current study and future studies that use the instrument. Alternatively, other measures such as the Cancer Survivors' Unmet Needs Measure (CaSUN) (Hodgkinson et al, 2007a), the Cancer Quality of Life Questionnaire (QLQ-C30) (McLachlan, Devins, & Goodwin, 1988), or the Brief Cancer Impact Assessment (BCIA) (Alfano, et al., 2005) should be considered. These measures have been validated for use with breast cancer survivors. Lipscomb, Gotay, and Snyder (2005) provide a comprehensive overview of validated assessments used in cancer research.

When assessing the needs of breast cancer survivors in Alaska it was important to gain the perspectives from survivors and their providers. The current mixed methods study sought to integrate quantitative and qualitative findings to draw informed conclusions and make purposeful recommendations for improving the care of breast cancer survivors in Alaska. Given the information gathered, it would be beneficial to conduct a qualitative study in which Alaskan breast cancer survivors are interviewed about current met and unmet needs to compare their responses to those of providers.

Based on the sample of women who completed the ABCNAS, it would be beneficial to target women from rural areas of Alaska in general and Alaska Native women in particular to gain their unique perspectives of the breast cancer experience. This is particularly important because breast cancer is the leading cancer among Alaska Native women (ANTHC, 2006). Alaska Native women living in rural areas of Alaska are faced with a host of additional issues with regard to geographical barriers, distance, lack of transportation, and separation from family and community when they are diagnosed with breast cancer. Previous research has examined the needs of rural breast cancer survivors (APA, 2000; Davis et al., 1998; Minstrell, Winzenberg, Rankin, Hughes, &

Walker, 2008; Wilson et al., 2000), but to date no needs assessments have been conducted specifically about the needs of breast cancer survivors within the Alaska Native population. More research is needed to identify the unique needs of Alaska Native breast cancer survivors.

In addition to breast cancer survivors, a needs assessment could be conducted for other types of cancer survivors in Alaska, namely prostate, colorectal, and lung cancer. Through conducting cancer-related research in Alaska, further guidelines and structures of care can be developed that best fit the needs of Alaskan cancer survivors. To move forward with improving coordinated care in Alaska and supplying breast cancer survivors with guidelines following treatment completion, it will be important to pilot test a survivorship care plan. Piloting a survivorship care plan in a hospital setting would test its effectiveness and patient and provider satisfaction. Results would provide feedback regarding the use of survivorship care plans and incorporating them in the standard of care in Alaska.

Women cope with breast cancer within social contexts that change over time. They face different challenges with breast cancer based on their age at diagnosis (Mosher & Danoff-Burg, 2005). Future research is needed to confirm the significant findings that younger breast cancer survivors have more difficulty with their relationships and concerns with sexuality and appearances than older breast cancer survivors. Previous research has confirmed that relationship issues and concerns with sexuality are frequent psychosocial areas of concern for younger breast cancer survivors (Baucom et al. 2006; Walsh et al., 2005). As Cimprich and colleagues (2002) identified, more research is needed to explore how life stages might affect recovery and adjustment in breast cancer survivors over time. In addition, it would be beneficial to explore use of programs developed specifically to address the different concerns of younger and older survivors from initial treatment into survivorship.

Lastly, it would be beneficial to explore needs of partners, such as family and friends, who support breast cancer survivors throughout their care continuum. Often partners, family members, and friends are overlooked in breast cancer services. The

experience of caring for a loved one with breast cancer can take a toll on the individual as well as place additional stress on the survivor-partner relationship. Previous research has explored quality of life of caregivers (Gaston-Johansson, Lachica, Fall-Dickerson, & Kennedy, 2004), impact of cancer on couples (Youngmee et al., 2008), and the perceived burden of caring for someone with breast cancer (Grunfeld et al., 2004). It can be challenging for primary caregivers to meet their own needs while working to meet the needs of a loved one dealing with cancer. A needs assessment to identify key challenges and issues for primary caregivers would provide direction for additional services that may help support caregivers while treating the cancer survivor.

Summary

Through this study, insight was gained from survivors and healthcare providers' perspectives about the needs of breast cancer survivors in Alaska. Breast cancer survivors experience a host of needs throughout their cancer journey. Survivors identified needs that often differed based on age at diagnosis and survivorship phase. Diverse direct and supportive healthcare providers offered unique perspectives of common challenges breast cancer survivors experience during treatment and follow-up care in Alaska. Healthcare providers identified barriers, system and service training gaps, areas of improvement, the roles of healthcare providers, and the unique challenges rural breast cancer survivors face when living in remote areas of Alaska.

Recommendations were developed and targeted to healthcare providers, hospital groups, and key community stakeholders (summarized in Table 44). The identified areas of need led to the following five broad recommendations: 1) address service gaps and improve communication; 2) address psychosocial needs; 3) address needs specific to rural breast cancer survivors; 4) improve coordination of care and 5) implement established survivorship care plan(s) within Alaska's healthcare system. These recommendations will increase awareness of the experiences and needs of breast cancer survivors in Alaska. Through working to meet these needs, breast cancer survivors and healthcare providers will experience greater collaboration and more cohesive delivery of services, leading to improved breast cancer-related care in Alaska.

Table 44

Summary of Recommendations to Key Groups for Improving Breast Cancer Services in Alaska

Healthcare Providers	Hospital Groups	Other Key Community Stakeholders	Rural Recommendations
• Work to improve addressing the psychosocial needs of BC survivors as a standard of care.	• Develop positions for breast cancer navigators at all major treatment hospitals.	• Continue to work toward improving coordinated cancer care in Alaska.	• Utilize telemedicine to provide medical and supportive care services to rural breast cancer survivors.
• Strive to screen for emotional need among all cancer patients during medical appointments (use the BSI).	• Consider providing cancer related medical visits using a group visit model.	• Continue to support programs that provide services to BC survivors in Alaska.	• Work to increase supportive care services to rural areas of Alaska.
• Improve coordination among private oncology offices, utilizing a multidisciplinary care approach.	• Consider incorporating a Patient-Centered Medical Home model for cancer patients during and following treatment completion	• Bring awareness to human resource offices & employers about what to expect of employees who are cancer survivors during and post-treatment.	• Increase support groups in rural areas of Alaska
• Increase communication about the potential cognitive, sexual, and psychological side effects of cancer treatment.	• Reevaluate the possibility of having a survivorship clinic or a breast cancer clinic in Alaska.	• Train oncology office personnel on importance of being responsive to BC survivors.	• Continue to work to recruit healthcare providers who have experience working with BC survivors in rural areas of Alaska.
• For direct-oncology providers, increase referrals to auxiliary services.	• Provide all cancer patients with the option of recording their medical appointments with their oncology provider.	• Support annual continuing education about best practices in cancer care for providers.	• Continue to support efforts of rural BC survivors to overcome the logistical barriers of receiving treatment in Alaska
• Encourage providers to become familiar with other disciplines that offer services to breast cancer survivors.	• Expand Oncology Rehabilitation services to other areas of Alaska.	• Secure funding to develop programs & polices to support women who are struggling financially.	• Continue to improve logistical barriers related to travel and accommodations

Table 44 continued

Healthcare providers	Hospital Groups	Other Key Community Stakeholders	Rural Recommendations
• Increase communication among direct oncology providers and primary care providers.	• Work to disperse information about supportive care services available to cancer survivors in Alaska.	• Continue to support cancer research efforts in Alaska.	• Expand already established programs which service BC survivors to rural areas of Alaska.
• Work to improve coordination of care from transitioning survivors back to primary care.	• Incorporate a Survivorship Care Plan as a standard part of treatment completion that is provided to all cancer patients.	• Advocate for the implementation of survivorship care plans as a part of standard of care.	• Create positions for breast cancer navigators who are responsible for following rural BC survivors during and following treatment.
• Allow survivors to record their medical appointments in order to decrease the amount providers repeat themselves.	• Consider incorporating mental health providers into oncology offices as a part of a collaborative care model.		
• Work to improve communication about diagnosis and treatment options with patients.	• Consider developing a program that is specific to age at diagnosis to better meet the needs of younger and older BC survivors.		
• Improve and make available alternative and complementary services for survivors.			

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Appendix A

Breast Cancer Needs Assessment Survey

BREAST CANCER NEEDS ASSESSMENT

Thank you for your interest in completing the
Breast Cancer Needs Assessment.

This study explores experiences and needs of women with histories of breast cancer. Findings will be used to:

- increase knowledge about the experience of breast cancer among Alaskan women
- increase information about services needed to better meet the needs of women with breast cancer
- develop recommendations for providers, policy makers, and administrators about how to improve services
- better meet the needs of Alaska women facing breast cancer

Thank you for being part of this very important project.

This survey is hosted by **Center for Behavioral Health Research and Services** with funding from the community.

UAA ALASKA PROVIDENCE Alaska Medical Center

Assessing the Needs of Alaska Women Diagnosed with Breast Cancer

Behavioral Health Research Services (BHRS)

Informed Consent Information

Names of Researchers: Jodi Barnett, Virginia Cress, and Christiane Brems
Contact Information 3401 East 42nd Street, Suite 200
Anchorage Alaska 99508
907-561-2880 (phone); 907-561-2895 (fax)
amjdb3@uaa alaska.edu (email)

WHAT IS THE REASON FOR THIS STUDY?

The reasons are to:

- *find out about the needs of Alaska women who are breast cancer survivors,*
- *increase our understanding about breast cancer in Alaska, and*
- *get information about services that need to be developed.*

This study will find out about ongoing needs of women with histories of breast cancer. This information will be given to caregivers so they can find better ways to help you.

WHO CAN PARTICIPATE?

You are invited to be in the study if you:

- *are a woman,*
- *are at least 18 years old,*
- *live in Alaska, and*
- *had a diagnosis of breast cancer at some time in your life*

WHAT DOES THE STUDY ASK PARTICIPANTS TO DO?

Women who choose to participate will complete a survey. Women can take the survey online, have it mailed to them, or can have it read to them over the phone. The online or hardcopy version of the survey takes about 30 minutes and about an hour over the phone.

The survey will focus on needs that arise due to being a survivor of breast cancer, how strong these needs are, and if they have been met. An important part of the survey is to find out if women can access the services they want and need.

WHAT ARE THE POTENTIAL BENEFITS AND RISKS?

Your participation in this study only takes some of your time. There are no personal benefits, but your willingness to share your experiences will help us make recommendations about how to improve services for women just like you.

There are no significant risks, though being part of this study may bring up some uncomfortable memories.

WHAT ABOUT CONFIDENTIALITY?

We keep all your answers completely private and confidential; we do not even need to know your name. We will not share your answers with anyone outside of our research group. We will report about the survey only with group averages and without revealing individual answers to anyone.

WHAT IF YOU DON'T WANT TO BE PART OF THE STUDY (ANYMORE)?

Your participation in this study is voluntary. You may stop at any time and you do not have to answer any questions you don't want to. Nothing will happen to you if you choose not to answer any questions or if you decide not to participate

WHAT IF YOU HAVE QUESTIONS?

You can ask questions at any time. If you want to talk to someone about the study, you can call Jodi Barnett (Project Coordinator) on Mondays to Fridays between 9 am and 5 pm. Her phone number is 907-561-2880.

If you have questions or concerns about your rights as a research participant, you can call us or the Vice Provost for Research at the University of Alaska Anchorage at 907-786-1000.

ARE YOU WILLING TO BE IN THE STUDY?

- *I have read or listened to the information on this consent form.*
- *I understand what the researchers are asking me about*
- *I understand that the survey is completely voluntary*
- *I understand that I can quit at any time*
- *I would like to complete this survey*

I understand and agree with all of the above statements:

Yes (if you check *yes* you will then go to the survey)
No (if you check *no* you will not be able to participate in the study)

IF YOU CHECKED THE 'YES' BOX...

... then *Thank You* for agreeing to take the following survey. Please go to the survey now. And please remember that you can stop at any time or call us with any questions or concerns. We appreciate your participation and willingness to share your experience in order to help others!

SECTION A: SCREENING QUESTIONS

Before you begin the needs assessment, we would like to ask you a few questions to make sure that you meet the study requirements.

1. **What is your gender?**

   [ ] Female
   [ ] Male [ineligible]

2. **Are you at least age 18 or older?**

   [ ] Yes
   [ ] No [17 or younger ineligible]

3. **Do you currently live in Alaska?**

   [ ] Yes
   [ ] No [ineligible]

4. **What is your age?**

   __ __

5. **When was your breast cancer first diagnosed?**

   __ __ Month __ __ __ __ Year

6. **What is your 5-digit zip code?**

   __ __ __ __ __

SECTION B. TREATMENTS AND SERVICES

In this section, we will explore your experience with
treatments and services
that are commonly used by women with breast cancer.

Please answer based on the experience you had most recently.

DIAGNOSTIC and SCREENING TESTS

What has been your experience with **diagnostic and screening tests** for breast cancer?

Check all that apply for each test	Breast Exam	Mammogram: Film	Mammogram: Digital	Breast Biopsy	Breast Ultrasound	PET	MRI
Received most recently in which year?	____ YEAR	____ YEAR	____ YEAR	____ YEAR	____ YEAR	____ YEAR	____ YEAR
I received these and was mostly satisfied	☐	☐	☐	☐	☐	☐	☐
I received these and was mostly dissatisfied	☐	☐	☐	☐	☐	☐	☐
I did not receive these services	☐	☐	☐	☐	☐	☐	☐
I did not receive these or was mostly dissatisfied **because**							
• I had no need for it	☐	☐	☐	☐	☐	☐	☐
• Did not help me	☐	☐	☐	☐	☐	☐	☐
• Painful or side effects	☐	☐	☐	☐	☐	☐	☐
• Provider not helpful	☐	☐	☐	☐	☐	☐	☐
• Setting was unfriendly	☐	☐	☐	☐	☐	☐	☐
• Care not coordinated	☐	☐	☐	☐	☐	☐	☐
• I refused did not want it	☐	☐	☐	☐	☐	☐	☐
• No insurance coverage	☐	☐	☐	☐	☐	☐	☐
• Wait was too long	☐	☐	☐	☐	☐	☐	☐
• Too expensive	☐	☐	☐	☐	☐	☐	☐
• Not available where I live	☐	☐	☐	☐	☐	☐	☐
• No transportation	☐	☐	☐	☐	☐	☐	☐
• No one offered it to me	☐	☐	☐	☐	☐	☐	☐
• Was not given enough information	☐	☐	☐	☐	☐	☐	☐

What would be the best way to provide you more information about **diagnostic and screening tests**?

Choose one:

☐ I do not want information
☐ Mailings or newsletters through the mail
☐ Electronic mailings or newsletters
☐ Consultation with a health care provider
☐ Website
☐ Books brochures magazines handouts
☐ Video, telephone, or online educational talks
☐ Conferences, seminars, workshops or in-person educational talks
☐ Medical journals and articles for professionals
☐ Other methods _____

COMMON BREAST CANCER TREATMENTS

What has been your experience with common treatments for breast cancer?

Check all that apply for each treatment	Lumpec-tomy	Full Partial Mastectomy	Chemo-therapy	Hormone Therapy	Radiation Therapy
Received most recently in which year?	____ YEAR	____ YEAR	____ YEAR	____ YEAR	____ YEAR
I received these and was mostly satisfied	☐	☐	☐	☐	☐
I received these and was mostly dissatisfied	☐	☐	☐	☐	☐
I did not receive these services	☐	☐	☐	☐	☐
For those services you did not receive or were mostly dissatisfied with, please check all reasons why					
• I had no need for it		☐	☐	☐	☐
• Did not help me		☐	☐	☐	☐
• Painful or side effects		☐	☐	☐	☐
• Provider not helpful		☐	☐	☐	☐
• Setting was unfriendly		☐	☐	☐	☐
• Care not coordinated		☐	☐	☐	☐
• I refused/did not want it		☐	☐	☐	☐
• No insurance coverage		☐	☐	☐	☐
• Wait was too long		☐	☐	☐	☐
• Too expensive		☐	☐	☐	☐
• Not available where I live		☐	☐	☐	☐
• No transportation		☐	☐	☐	☐
• No one offered it to me		☐	☐	☐	☐
• Was not given enough information		☐	☐	☐	☐

What would be the best way to provide you more information about common treatments?

Choose one:

☐ I do not want information
☐ Mailings or newsletters through the mail
☐ Electronic mailings or newsletters
☐ Consultation with a health care provider
☐ Website
☐ Books, brochures, magazines, handouts
☐ Video, telephone, or online educational talks
☐ Conferences, seminars, workshops or in-person educational talks
☐ Medical journals and articles for professionals
☐ Other methods _____

ADDITIONAL TREATMENTS and SERVICES

What has been your experience with <u>additional treatments and services</u> for breast cancer?

Check all that apply for <u>each</u> treatment	Breast Prosthesis	Recon-structive Surgery	Physical Therapy	Clinical Trials	Second Opinion	Genetic Testing
Received <u>most recently</u> in which year?	____ YEAR	____ YEAR	____ YEAR	____ YEAR	____ YEAR	____ YEAR
I received these and was mostly satisfied						
I received these and was mostly dissatisfied						
I did not receive these services						
For those services you did not receive or were mostly dissatisfied with please check all reasons why						
• I had no need for it						
• Did not help me						
• Painful or side effects						
• Provider not helpful						
• Setting was unfriendly						
• Care not coordinated						
• I refused/did not want it						
• No insurance coverage						
• Wait was too long						
• Too expensive						
• Not available where I live						
• No transportation						
• No one offered it to me						
• Was not given enough information						

What would be the best way to provide you more information about <u>additional treatments and services</u>?

Choose one:

- I do not want information
- Mailings or newsletters through the mail
- Electronic mailings or newsletters
- Consultation with a health care provider
- Website
- Books brochures, magazines, handouts
- Video, telephone or online educational talks
- Conferences, seminars, workshops or in-person educational talks
- Medical journals and articles for professionals
- Other methods _____

ALTERNATIVE and COMPLEMENTARY TREATMENTS

What has been your experience with **alternative complementary treatments** for breast cancer?

Check all that apply for each treatment	**Nutrition and Diet**	**Supplements and Herbs**	**Massage, Exercise, Yoga, etc.**	**Relaxation, Meditation, Imagery, etc.**
Received most recently in which year?	____ YEAR	____ YEAR	____ YEAR	____ YEAR
I received these and was mostly satisfied	☐	☐	☐	☐
I received these and was mostly dissatisfied	☐	☐	☐	☐
I did not receive these services	☐	☐	☐	☐
For those services you did not receive or were mostly dissatisfied with please check all reasons why				
• I had no need for it	☐	☐	☐	☐
• Did not help me	☐	☐	☐	☐
• Painful or side effects	☐	☐	☐	☐
• Provider not helpful	☐	☐	☐	☐
• Setting was unfriendly	☐	☐	☐	☐
• Care not coordinated	☐	☐	☐	☐
• I refused/did not want it	☐	☐	☐	☐
• No insurance coverage	☐	☐	☐	☐
• Wait was too long	☐	☐	☐	☐
• Too expensive	☐	☐	☐	☐
• Not available where I live	☐	☐	☐	☐
• No transportation	☐	☐	☐	☐
• No one offered it to me	☐	☐	☐	☐
• Was not given enough information	☐	☐	☐	☐

What would be the best way to provide you more information about **alternative complementary treatments**?

Choose one:

☐ I do not want information
☐ Mailings or newsletters through the mail
☐ Electronic mailings or newsletters
☐ Consultation with a health care provider
☐ Website
☐ Books, brochures, magazines, handouts
☐ Video, telephone, or online educational talks
☐ Conferences, seminars, workshops or in-person educational talks
☐ Medical journals and articles for professionals
☐ Other methods _____

FORMAL PSYCHOLOGICAL SERVICES

What has been your experience with formal psychological services for breast cancer?

Check all that apply for each service	Individual Counseling	Family Counseling	Couples Counseling	Counseling for Spouse Partner	Counseling for Child(ren)
Received most recently in which year?	____ YEAR	____ YEAR	____ YEAR	____ YEAR	____ YEAR
I/we received these and felt mostly satisfied		☐	☐	☐	☐
I/we received these and felt mostly dissatisfied		☐	☐	☐	☐
I/we did not receive these services		☐	☐	☐	☐
For those services you did not receive or were mostly dissatisfied with please check all reasons why					
• I/we had no need for it		☐	☐	☐	☐
• Did not help me/us		☐	☐	☐	☐
• Painful or side effects		☐	☐	☐	☐
• Provider not helpful		☐	☐	☐	☐
• Setting was unfriendly		☐	☐	☐	☐
• Care not coordinated		☐	☐	☐	☐
• Refused did not want it		☐	☐	☐	☐
• No insurance coverage		☐	☐	☐	☐
• Wait was too long		☐	☐	☐	☐
• Too expensive		☐	☐	☐	☐
• Not available where I live		☐	☐	☐	☐
• No transportation		☐	☐	☐	☐
• No one offered it to me		☐	☐	☐	☐
• Was not given enough information		☐	☐	☐	☐

What would be the best way to provide you more information about formal psychological services?

Choose one:

☐ I do not want information
☐ Mailings or newsletters through the mail
☐ Electronic mailings or newsletters
☐ Consultation with a health care provider
☐ Website
☐ Books brochures, magazines, handouts
☐ Video, telephone, or online educational talks
☐ Conferences, seminars, workshops or in-person educational talks
☐ Medical journals and articles for professionals
☐ Other methods _____

ORGANIZED SUPPORT SERVICES

What has been your experience with organized support services for breast cancer?

Check all that apply for each service	Support Groups	Online Support Groups	One-on-One Peer Support	Telephone Hotline Support	Spiritual Support
Received most recently in which year?	____ YEAR	____ YEAR	____ YEAR	____ YEAR	____ YEAR
I received these and was mostly satisfied					
I received these and was mostly dissatisfied					
I did not receive these services					
For those services you did not receive or were mostly dissatisfied with please check all reasons why					
• I had no need for it					
• Did not help me					
• Painful or side effects					
• Provider not helpful					
• Setting was unfriendly					
• Care not coordinated					
• I refused did not want it					
• No insurance coverage					
• Wait was too long					
• Too expensive					
• Not available where I live					
• No transportation					
• No one offered it to me					
• Was not given enough information					

What would be the best way to provide you more information about organized support services?

Choose one:

- I do not want information
- Mailings or newsletters through the mail
- Electronic mailings or newsletters
- Consultation with a health care provider
- Website
- Books brochures magazines handouts
- Video, telephone or online educational talks
- Conferences seminars workshops or in-person educational talks
- Medical journals and articles for professionals
- Other methods _____

SECTION C. COMMUNICATION WITH PROVIDERS

In this section, we will explore your experience with
how well providers communicated with you
when they treated you for breast cancer.

Please answer based on the experience you had most recently.

COMMUNICATION WITH PROVIDERS

What has been your experience with **communication with providers** who helped you with treatments and services for your breast cancer?

Were your providers up-to-date on the best treatments and services for your breast cancer?

Choose one answer for each type of provider	**Was up-to-date on the best treatments**					
	Strongly Disagree	**Disagree**	**Agree**	**Strongly Agree**	**Not applicable**	**Did not have this type of provider**
Surgeon						
Radiation oncologist						
Oncologist						
Primary care physician						
Second opinion provider						
Nurse/nurse practitioner						
Physician assistant						
Physical therapist						
Alternative/complementary care provider						
Nutritionist dietician						
Psychologist counselor						

Did your providers offer you a variety of treatment and service options for your breast cancer?

Choose one answer for each type of provider	**Offered a variety of treatment options**					
	Strongly Disagree	**Disagree**	**Agree**	**Strongly Agree**	**Not applicable**	**Did not have this type of provider**
Surgeon						
Radiation oncologist						
Oncologist						
Primary care physician						
Second opinion provider						
Nurse/nurse practitioner						
Physician assistant						
Physical therapist						
Alternative/complementary care provider						
Nutritionist/dietician						
Psychologist counselor						

COMMUNICATION WITH PROVIDERS, Continued

Did your providers communicate well with each other about treatments and services for your breast cancer?

Choose one answer for each type of provider	Communicated well with other providers					
	Strongly Disagree	Disagree	Agree	Strongly Agree	Not applicable	Did not have this type of provider
Surgeon		☐		☐		☐
Radiation oncologist		☐		☐		☐
Oncologist		☐		☐		☐
Primary care physician		☐		☐		☐
Second opinion provider		☐		☐		☐
Nurse nurse practitioner		☐		☐		☐
Physician assistant		☐		☐		☐
Physical therapist		☐		☐		☐
Alternative/complementary care provider		☐		☐		☐
Nutritionist/dietician		☐		☐		☐
Psychologist counselor		☐		☐		☐

Did your providers make appropriate referrals for additional treatment and services for your breast cancer?

Choose one answer for each type of provider	Made appropriate referrals					
	Strongly Disagree	Disagree	Agree	Strongly Agree	Not applicable	Did not have this type of provider
Surgeon		☐		☐		☐
Radiation oncologist		☐		☐		☐
Oncologist		☐		☐		☐
Primary care physician		☐		☐		☐
Second opinion provider		☐		☐		☐
Nurse nurse practitioner		☐		☐		☐
Physician assistant		☐		☐		☐
Physical therapist		☐		☐		☐
Alternative/complementary care provider		☐		☐		☐
Nutritionist/dietician		☐		☐		☐
Psychologist counselor		☐		☐		☐

COMMUNICATION WITH PROVIDERS, Continued

Did your providers listen to you and treat you with respect and caring?

Choose one answer for each type of provider	**Listened and treated me with respect and caring**					
	Strongly Disagree	**Disagree**	**Agree**	**Strongly Agree**	**Not applicable**	**Did not have this type of provider**
Surgeon	☐	☐	☐	☐	☐	☐
Radiation oncologist	☐	☐	☐	☐	☐	☐
Oncologist	☐	☐	☐	☐	☐	☐
Primary care physician	☐	☐	☐	☐	☐	☐
Second opinion provider	☐	☐	☐	☐	☐	☐
Nurse/nurse practitioner	☐	☐	☐	☐	☐	☐
Physician assistant	☐	☐	☐	☐	☐	☐
Physical therapist	☐	☐	☐	☐	☐	☐
Alternative/complementary care provider	☐	☐	☐	☐	☐	☐
Nutritionist/dietician	☐	☐	☐	☐	☐	☐
Psychologist/counselor	☐	☐	☐	☐	☐	☐

SECTION D. PHYSICAL WELLBEING

In this section we will explore how breast cancer may have affected
your physical wellbeing
(such as being in pain or experiencing side effects from treatment).

Please answer based on the experience you had most recently.

PHYSICAL WELLBEING

Following is a list of physical concerns that often present challenges for women with breast cancer

Please rate for how long each of the following symptoms has been a problem for you since your diagnosis with breast cancer

Please choose only ONE answer for each physical challenge	Never been a problem	Short-term problem	Long-term problem that did or will go away	Long-term problem that might not go away
Difficulty walking or climbing stairs	☐	☐	☐	☐
Fatigue or tiredness	☐	☐	☐	☐
Breathing difficulties	☐	☐	☐	☐
Night sweats	☐	☐	☐	☐
Appetite loss	☐	☐	☐	☐
Nausea	☐	☐	☐	☐
Pain	☐	☐	☐	☐
Joint pain or muscle aches	☐	☐	☐	☐
Memory loss	☐	☐	☐	☐
Concentration difficulties	☐	☐	☐	☐
Sleep difficulties	☐	☐	☐	☐
Hair loss	☐	☐	☐	☐
Hot flashes	☐	☐	☐	☐
Fertility	☐	☐	☐	☐
Vaginal dryness or painful intercourse	☐	☐	☐	☐
Abnormal uterine bleeding	☐	☐	☐	☐
Lymphedema [swelling in arm(s)]	☐	☐	☐	☐
Neuropathy [tingling or numbness in hands or feet]	☐	☐	☐	☐
Weight gain or loss	☐	☐	☐	☐
Radiation burns	☐	☐	☐	☐
Loss of bone density	☐	☐	☐	☐
Mouth sores	☐	☐	☐	☐

What would be the best way to provide you with more information about **physical symptoms**?

Choose one:

- [ ] I do not want information
- [ ] Mailings or newsletters through the mail
- [ ] Electronic mailings or newsletters
- [ ] Consultation with a health care provider
- [ ] Website
- [ ] Books, brochures, magazines, handouts
- [ ] Video, telephone, or online educational talks
- [ ] Conferences, seminars, workshops or in-person educational talks
- [ ] Medical journals and articles for professionals
- [ ] Other methods _____

SECTION E. PSYCHOLOGICAL WELLBEING

In this section we will explore how breast cancer may have affected
your psychological wellbeing
(such as feeling anxious, depressed, or lonely).

Please answer based on the experience you had most recently.

PSYCHOLOGICAL WELLBEING

Following is a list of psychological symptoms that often present challenges for women with breast cancer

Please rate how long each of the following psychological symptoms has been a problem for you since your diagnosis with breast cancer

Please choose only ONE answer for each psychological symptom	Never been a problem	Short-term problem	Long-term problem that did or will go away	Long-term problem that might not go away
Hopelessness	☐	☐	☐	☐
Feeling overwhelmed	☐	☐	☐	☐
Depressed	☐	☐	☐	☐
Stressed	☐	☐	☐	☐
Anxious	☐	☐	☐	☐
Angry	☐	☐	☐	☐
Fear of cancer returning	☐	☐	☐	☐
Fear of cancer spreading	☐	☐	☐	☐
Fear of pain	☐	☐	☐	☐
Worries about appearance after surgery	☐	☐	☐	☐
Worries about sexuality	☐	☐	☐	☐
Isolation or loneliness	☐	☐	☐	☐
Worries about the future	☐	☐	☐	☐
Fear of death	☐	☐	☐	☐
Thoughts of being useless	☐	☐	☐	☐
Guilt or shame	☐	☐	☐	☐
Loss of control	☐	☐	☐	☐
Spiritual doubts	☐	☐	☐	☐
Spouse/partner troubled by my diagnosis	☐	☐	☐	☐
Child(ren) troubled by my diagnosis	☐	☐	☐	☐
Other family members troubled by my diagnosis	☐	☐	☐	☐
Stress in my relationship with spouse/partner because of my diagnosis	☐	☐	☐	☐
Stress in relationship with my child(ren) because of my diagnosis	☐	☐	☐	☐

What would be the best way to provide you with more information about **psychological symptoms**?

Choose one:

- [ ] I do not want information
- [ ] Mailings or newsletters through the mail
- [ ] Electronic mailings or newsletters
- [ ] Consultation with a health care provider
- [ ] Website
- [ ] Books, brochures, magazines, handouts
- [ ] Video, telephone, or online educational talks
- [ ] Conferences, seminars, workshops or in-person educational talks
- [ ] Medical journals and articles for professionals
- [ ] Other methods _____

SECTION F. DAILY LIVING

In this section we will explore how breast cancer may have affected
your daily life
(such as financial, occupational, and legal concerns).

Please answer based on the experience you had most recently.

DAILY LIVING

Following is a list of **issues often encountered in daily living** by women with breast cancer We are interested in the degree to which you encountered these and if you were able to get help in dealing with them

Please rate how long each of the following life circumstances has been a problem for you since your diagnosis with breast cancer

Please choose only ONE answer for each life circumstance	Never been a problem	Short-term problem	Long-term problem that did or will go away	Long-term problem that might not go away
Economic Financial Issues				
• Employment	☐	☐	☐	☐
• Financial difficulties	☐	☐	☐	☐
• Health insurance	☐	☐	☐	☐
• Financial assistance or government benefits	☐	☐	☐	☐
• Keeping up with household chores	☐	☐	☐	☐
• Finding child care	☐	☐	☐	☐
Legal Issues				
• Life insurance	☐	☐	☐	☐
• End-of-life choices	☐	☐	☐	☐
• Legal services	☐	☐	☐	☐

DAILY LIVING

What has been your experience with being able to access services to help you deal with issues encountered in daily living that arose due to breast cancer?

Check all that apply for each service	Financial/ Economic Issues	Legal Issues
Received services for these most recently in which year?	____ YEAR	____ YEAR
I received services for these and was mostly satisfied	[ ]	[ ]
I received services for these and was mostly dissatisfied	[ ]	[ ]
I did not receive services for these	[ ]	[ ]
I did not receive services for these or was mostly dissatisfied **because**		
• I had no need for it	[ ]	[ ]
• Did not help me	[ ]	[ ]
• Provider not helpful	[ ]	[ ]
• Setting was unfriendly	[ ]	[ ]
• Services not coordinated	[ ]	[ ]
• I refused did not want it	[ ]	[ ]
• No insurance coverage	[ ]	[ ]
• Wait was too long	[ ]	[ ]
• Too expensive	[ ]	[ ]
• Not available where I live	[ ]	[ ]
• No transportation	[ ]	[ ]
• No one offered it to me	[ ]	[ ]
• Was not given enough information	[ ]	[ ]

What would be the best way to provide you more information about issues encountered in daily living?

Choose one:

[ ] I do not want information
[ ] Mailings or newsletters through the mail
[ ] Electronic mailings or newsletters
[ ] Consultation with a health care provider
[ ] Website
[ ] Books brochures magazines handouts
[ ] Video, telephone, or online educational talks
[ ] Conferences, seminars, workshops or in-person educational talks
[ ] Medical journals and articles for professionals
[ ] Other methods _____

SECTION G: DEMOGRAPHIC QUESTIONS

Before ending the needs assessment, we would like to ask you a few questions about yourself (such as number of children, education, employment).

1. **What is the current status of your breast cancer?**
   Check all that apply
   - ☐ This is the first time I am dealing with breast cancer
   - ☐ My physician has indicated there no longer is any evidence of the cancer
   - ☐ My cancer has spread to other part of my body
   - ☐ I am currently dealing with a recurrence

2. **For the most recent diagnosis with breast cancer, what was the stage of your disease?**
   Choose one:
   - ☐ Stage 0
   - ☐ Stage 1
   - ☐ Stage 2 (including 2a, 2b, 2c)
   - ☐ Stage 3 (including 3a, 3b, 3c)
   - ☐ Stage 4
   - ☐ Not sure

3. **Please check the primary location where you received your original diagnosis and the majority of treatment?**

	Diagnosis	Primary Treatment	Complementary Treatment	Psychological Services	Second Opinion
Outside of Alaska	☐	☐	☐	☐	☐
If in Alaska, where mostly?					
• Anchorage	☐	☐	☐	☐	☐
• Fairbanks	☐	☐	☐	☐	☐
• Juneau	☐	☐	☐	☐	☐
• Hub community	☐	☐	☐	☐	☐
• Other place in Alaska	☐	☐	☐	☐	☐
How far did you have to travel by car OR air:					
• Estimated miles:	_____ miles	_____ miles	_____ miles	_____ miles	_____ miles
• Estimated airline hours	_____ hours	_____ hours	_____ hours	_____ hours	_____ hours

4. **Including yourself, how many people live in your household?**
   __ __ insert number

5. **With whom do you currently live**
   Check all that apply.
   - ☐ Spouse/partner
   - ☐ Children
   - ☐ Other family besides partner, spouse or children
   - ☐ Friend or roommate
   - ☐ Other

6. **How many children do you have, if any?**

__ __ insert number

7. **What is the age of your youngest child?**

__ __

8. **What do you consider your primary cultural heritage?**
Check one response only:

- African American
- Alaska Native
- Asian Pacific Islander
- Biracial Mixed heritage
- Caucasian
- Hispanic or Latina Latino
- Native American
- Native Hawaiian
- Other
- Don't know OR don't want to say

8a If you are Alaska Native – please specify

- Aleut
- Athabascan
- Inupiat
- Haida
- Tlingit
- Tsimpshian
- Yupik
- Other AK Native

9. **What is your highest level of education?**
Check one response only:

- Less than high school
- Some high school
- High school or GED
- Some college
- Associate's degree
- Bachelor's degree
- Graduate degree
- Don't know OR don't want to say

10. **What is your current employment status?**
Check one response only:

- Working full-time
- Working part-time
- Full-time student
- Full-time homemaker
- On medical leave
- Unemployed
- Retired
- Receiving disability income
- Other
- Don't know OR don't want to say

11. **Do you have health insurance or access to free healthcare?**
Choose one main source

- No insurance
- Private insurance
- Medicare
- Medicaid
- VA healthcare benefits
- IHS or tribal healthcare
- Other access to affordable healthcare
- Don't know OR don't want to say

12. What is your approximately total gross household income per year?

Check one response only:

- ☐ Less than $10,000
- ☐ $10,000 to $19,999
- ☐ $20,000 to $29,999
- ☐ $30,000 to $39,999
- ☐ $40,000 to $49,999
- ☐ $50,000 to $59,999
- ☐ $60,000 to $69,999
- ☐ $70,000 to $79,999
- ☐ $80,000 to $89,999
- ☐ $90,000 to $99,999
- ☐ More than $100,000 per year
- ☐ Don't know OR don't want to say

13. Where did you <u>first</u> hear about this breast cancer needs assessment survey?

Check one response only:

- ☐ Anchorage Daily News
- ☐ Other Anchorage newspaper
- ☐ Other newspaper outside Anchorage
- ☐ Received an Email
- ☐ Hospital or other health care facility
- ☐ Health care provider
- ☐ Radio
- ☐ Television
- ☐ Conference or other event
- ☐ Newsletter, Poster, or Flyer
- ☐ Friend or relative
- ☐ Other

THANK YOU FOR COMPLETING THIS SURVEY.

If you have additional comments or thoughts that would help us better understand the needs of women with breast cancer, please include them here.

Appendix B

BCNA Survey Internal Review Board Approval Letter

UAA UNIVERSITY *of* ALASKA ANCHORAGE
Office of Research and Graduate Studies

September 26, 2008

Dr. Christiane Brems
Behavioral Health Research and Services
University of Alaska Anchorage
3211 Providence Drive
Anchorage, Alaska 99508-4614

Dear Dr. Brems:

Your Institutional Review Board (IRB) proposal entitled *Assessing the Needs of Alaska Women Diagnosed with Breast Cancer* meets the U.S. Department of Health and Human Services requirements for the protection of human research subjects (45 CFR 46 as amended/revised) as being exempt from full Board review.

In keeping with the usual policies and procedures of the IRB, your research project now has preliminary approval with suggested minor revisions in order to begin the research process. This approval is contingent upon final approval of the survey instrument.

On behalf of the Board, I want to extend my best wishes to you for success in accomplishing the objectives of your proposed study. I look forward to receiving the survey in the near future.

Sincerely,

Joanne K. Thordarson, M.S.
Research Compliance Administrator
Institutional Review Board

cc: Faculty Services
Dean James Liszka, College of Arts and Sciences

Appendix C

Key Informant Consent Form

Meeting the Needs of Breast Cancer Survivors in Alaska: Survivors' and Healthcare Providers' Perspectives

Researcher:
Virginia Cress Parret MS asvcc@uaa.alaska.edu
Clinical and Community Psychology PhD Program
University of Alaska Anchorage and Fairbanks
Office- (907) 440-1464

Research Supervisor:
Dr. Christiane Brems afch@uaa.alaska.edu
University of Alaska Anchorage
Dissertation Chair
Office- (907) 786-6381

PURPOSE AND BACKGROUND

As a doctoral student in the Clinical and Community Psychology Program, I am conducting a study exploring healthcare providers' perception of the needs of breast cancer survivors related to treatment and services, communication with healthcare providers, physical symptoms, psychological symptoms, and daily living challenges. You are invited to participate in this study because you are a healthcare provider practicing in the state of Alaska who has experience working with breast cancer survivors.

I am interested in your opinions and perceptions about the needs of breast cancer survivors in Alaska. If you choose to participate, you will be interviewed for about 15 to 60 minutes at a site that is convenient for you. You will be asked your views and experiences regarding the met and unmet needs of breast cancer survivors in Alaska. I will make notes and the interview will be audiotaped. The recording will be used only to assure accurate data collection and for data analysis purposes. The tape will be destroyed one year after all analyses and manuscripts have been completed and distributed.

CONFIDENTIALITY

Your responses in the interview will be confidential. All the materials from this study, including the written notes and audiotape, will be kept in a secure file cabinet in the researchers' offices to which only they have access. Data will be compiled in such a way that you cannot be identified. Your name, address, or any other identifiable information about you will not be attached to any of your responses, or to any reports or publications describing the results of this study. Though direct quotes from you may be used in the results of this study, your name and other identifying information will be kept anonymous.

VOLUNTARY NATURE OF PARTICIPATION

Your participation in this study is voluntary. You may stop at any time and you do not have to answer any questions you do not want to. Nothing will happen to you if you choose not to answer any questions or if you decide not to participate.

COSTS AND COMPENSATION

There are no financial costs to you for participating in this study. You will receive a Fred Meyer's gift card for $50 for your time and efforts in participating in this study.

POTENTIAL BENEFITS AND RISKS

Your participation in this study only requires a commitment of time on your part. However, if you decide to participate, your willingness to share your experiences and knowledge may provide valuable insights for meeting the needs of breast cancer survivors in Alaska. There are

no foreseeable risks or benefits to you personally with respect to your personal or professional status from participation in this study.

QUESTIONS

If you have any questions about this study, please contact Virginia Cress Parret at (907) 440-1464 or Dr. Christiane Brems, Dissertation Chair, at (907) 786-6381. If you have any questions or concerns about your rights as a research participant, please contact Dr. Robert White, the UAA Vice Provost for Research and Graduate Studies at (907) 786-1099. Upon completion of the study, a final copy of the dissertation will be available for public review through the University of Alaska Anchorage and the University of Alaska Fairbanks libraries.

SIGNATURE

Your signature below means that you have read the information above and agree to participate in this study. If you have any questions, please feel free to ask them now or at any time during the study. Consent will be provided by participants signing that they understand and agree with the following statements:

- *I have read or listened to the information on this consent form*
- *I understand what is in the consent form and had opportunity to ask questions.*
- *I understand that the study is completely voluntary.*
- *I understand that I can quit at any time.*
- *I would like to participate in this study.*

With my signature below, I indicate that I understand and agree with all of the above statements:

Signature_____ Date _____

Print Name _____

Appendix D

Key Informant Interview Protocol

Key Informant Interview Guide

Interview Date:	Location:
Time Started:	Time Ended:
Interviewer:	Dates and Types of Contacts:
Remarks:	

Point 1

- This key informant interview is part of a pilot study exploring the needs of female breast cancer survivors in Alaska. It is the purpose of this study to begin to accumulate information about Alaskan healthcare providers' perceptions of these met and unmet needs.
- More specifically, this study will examine healthcare providers' perception of the needs of breast cancer survivors related to treatment and services, communication with healthcare providers, physical symptoms, psychological symptoms, and daily living challenges.

Point 2

Administer the informed consent

- Do you have any questions for me regarding the informed consent?
- As stated in the informed consent, I would like to record our conversation.
- Once the interview is done, the recording is used strictly to transcribe what your answers were, but without identifying who you are personally.
- Do you have any questions about the recording?

Start tape

Interview Questions

1. *To help give me a context for your answers, could you please give me a brief summary of what your experience has been with working with breast cancer survivors in Alaska?*
2. *Based on the synopsis provided were you surprised by the findings?*
    a. *Should there by additions or deletions based on your experience working with breast cancer survivors?*
3. *What are some of the circumstances that contribute to the identified unmet needs?*
4. *What barriers currently exist to meeting the needs of breast cancer survivors?*
5. *How do service gaps contribute to the unmet needs?*

6. *What role does access to services play in meeting the needs of breast cancer survivors?*
7. *How can these identified primary needs and unmet needs be addressed?*
8. *Are there system changes that may help to better meet the needs of breast cancer survivors?*
9. *What role do cancer care plans play and do you think they are used effectively?*
10. *What role can healthcare providers play in helping to better meet the needs of survivors in Alaska?*
11. *How could these ideas fit into the existing care structure currently in place?*
12. *Can you think of anything else related to meeting the needs of breast cancer survivors in Alaska?*

Respondent demographics

Gender (Circle): *Female* *Male*
Age (in years):
Ethnicity/Race:
Position and Degree:
Professional Years of Experience:
Professional Years of Experience in Alaska:
Specialty Areas:

Closure

Complete Data: Check to see that you have complete data: be sure that every major question was covered.

Consent Form: Make sure the participant has a copy of the consent form and has the name and phone number of relevant project staff should the participant want additional information about the study or thinks of something later.

- I really appreciate that you were willing to talk to me.
- The information you gave me is going to be very helpful.
- Thank you very much for your time.

Stop tape

Appendix E

Providence Alaska Medical Center Permission to Use Archival Data

Providence Alaska Medical Center
Approval Letter for Student Projects

PROVIDENCE
Alaska
Medical Center

Re: Assessing the Needs of Alaska Women Diagnosed with Breast Cancer research proposal

Dear Virginia,

Thank you for your request to utilize data obtained from the Cancer Needs Assessment Survey for the purposes of your doctoral dissertation which was considered by Providence Alaska Medical Center (PAMC) on June 16th, 2009.

Providence Alaska Medical Center EBP/Research Council approves this use of the dataset. We ask that you adhere to the guidelines set forth by the UAA BHRS in their approval letter dated May 18, 2009.

You must inform PAMC when the research has been completed as well as submit in writing the outcome of your project.

Any serious adverse events or significant change which occurs in connection with this study and/or which may alter its ethical considerations must be reported immediately to PAMC, your university and the IRB where approval was gained.

Good luck to you on the project and your dissertation.

Yours sincerely

Carrie Doyle RN, MSN, CCNS, CEN
Director of Nursing Practice
PAMC Nursing Professional Development Department
carrie.doyle@providence.org
907-212-6005

Stacey Medeiros, CHRC
Research Support Services
Providence Health Systems, Alaska
stacey.medeiros@providence.org
907-212-3629

Appendix F

University of Alaska Permission to Use Archival Data

UAA UNIVERSITY of ALASKA ANCHORAGE
Behavioral Health Research & Services (BHRS)

May 18, 2009

Virginia Cress, M.S.
601 Clippership Ct.
Anchorage, AK 99515

Dear Ms. Cress:

Thank you for your request to utilize the CBHRS Cancer Needs Assessment Survey dataset for purposes of your doctoral dissertation in the Ph.D. Program in Clinical-Community Psychology. After having reviewed your request, we have decided that this project is worthwhile and we are granting you permission to use the dataset for your stated purposes.

Permission is granted with the understanding that the data will not be not removed from the CBHRS premises (physical or electronic) and that all data analyses will be conducted from the CBHRS research offices at 42nd and Dale Street. It is also understood that the CBHRS Co-Directors will have the opportunity to review and comment upon all manuscripts that will be developed based upon these data, including your doctoral dissertation. It is understood that you have also secured permission from relevant individuals at Providence Alaska Medical Center to use this dataset, as the original project was a collaborative effort. Finally, it is understood that you will be submitting a proposal to the UAA Institutional Review Board seeking approval to use these data.

Please keep me posted on the progress of your work and let me know if you need any assistance. Good luck to you with your dissertation - you have chosen an important topic and BHRS is honored to be able to contribute valuable data.

Best wishes,

Mark E. Johnson, Ph.D.

Cc: Virginia Mongeau, BHRS Data Manager
Cindy Green, BHRS Business Manager

PO Box 241626 • Anchorage, Alaska 99524 • T 907.561.2880 • F 907.561.2895 • anbhrs@uaa.alaska.edu

Appendix G

Phase One Internal Review Board Approval Letters

UAA UNIVERSITY of ALASKA ANCHORAGE

Office of Research and Graduate Studies

September 16, 2009

Virginia C. Cress, MS
Center for Behavioral Health Research and Services
University of Alaska Anchorage
3211 Providence Drive
Anchorage, Alaska 99508-4614

Dear Ms. Cress:

Your Institutional Review Board (IRB) proposal entitled *Meeting the Needs of Breast Cancer Survivors in Alaska Survivors' and healthcare Providers' Perspectives* meets the U.S. Department of Health and Human Services requirements for the protection of human research subjects (45 CFR 46 as amended/revised) as being exempt from full Board review. In keeping with the usual policies and procedures of the IRB, your research project is approved.

Therefore, you have permission to begin data collection for your study. If this study goes beyond one year from the date of this submission, you will need to submit a Progress Report (see http://www.uaa.alaska.edu/research/ric/irb/documents.cfm) for approval to continue the research and please submit a Final Report at the end of the project.

Please report promptly proposed changes in the research protocol for IRB review and approval.

On behalf of the Board, I want to extend my best wishes for success in accomplishing the objectives of your proposed study.

Sincerely,

Joanne K. Thordarson, M.S.
Research Compliance Administrator
Institutional Review Board

cc: Dr. Christiane Brems, Center for Behavioral Health Research and Services
Dean James Liszka, College of Arts and Sciences

Research &
Graduate Studies
UNIVERSITY of ALASKA ANCHORAGE

3211 Providence Drive
Anchorage, Alaska 99508-4614
907.786.1436 • F 907.786.1491
www.uaa.alaska.edu/research

November 22, 2010

Virginia Cress Parret, M.S
7101 Spruce Street
Anchorage, AK 99507

Dear Ms Cress Parret:

This letter is in response to your request for continued Institutional Review Board (IRB) approval of your research project entitled *Meeting the Needs of Breast Cancer Survivors in Alaska. Survivors' and Heathcare Providers' Perspectives.*

This project was originally reviewed by the IRB in September 16, 2009. Your progress report states that you have had no problems with data collection, there are no changes to your protocols, and you would like an extension of IRB approval Your request is hereby granted.

Should data collection extend beyond one year from the date of this letter, please submit another Progress Report for continuation of IRB approval or a Final Report after you have completed your project. These forms are available at http://www.uaa.alaska.edu/research/ric/irb/documents.cfm.

On behalf of the entire Board, I wish you continued success with your study.

Sincerely,

Dianne Toebe

Dr. Dianne Toebe
Co-Chair, UAA Institutional Review Board

cc: Dr. Christiane Brems, Center for Behavioral Health Research and Services
Dean James Liszka, College of Arts and Sciences

Appendix H

Phase Two Internal Review Board Approval Letter

Research & Graduate Studies
UNIVERSITY of ALASKA ANCHORAGE

32 Providence Drive
Anchorage, Alaska 99508-4614
(907) 786-1960 • FAX (907) 786-4759
www.uaa.alaska.edu/research

November 29, 2010

Virginia Cress Parret, M.S.
7101 Spruce Street
Anchorage, AK 99507

Dear Ms. Cress Parret:

Your proposal entitled "Phase Two. Meeting the Needs of Breast Cancer Survivors in Alaska: Survivors' and Healthcare Providers' Perspectives" received an expedited review and was granted approval with minor revisions Thank you for a copy of these revisions. Therefore, in keeping with the usual policies and procedures of the UAA Institutional Review Board, your proposal is judged as fully satisfying the U.S. Department of Health and Human Services requirements for the protection of human research subjects (45 CFR 46 as amended/revised). This constitutes approval for you to conduct the study.

This approval is in effect for one year. If the study extends beyond a year from the date of this submission, you are required to submit a progress report and to request continuing approval of your project from the Board. At the conclusion of your research, submit the required final report to the IRB. These report forms are available at the IRB website at http:/ www.uaa.alaska.edu/research/rtc/irb/documents.cfm.

Please report promptly proposed changes in the research protocol for IRB review and approval Also, report to the IRB any injuries or other unanticipated or adverse events involving risks or harms to human research subjects or others.

On behalf of the Board, I wish to extend my best wishes for success in accomplishing your objectives

Sincerely,

Dr. Dianne Toebe

Dr Dianne Toebe
Co-Chair, Institutional Review Board

cc: Dr. Christiane Brems, Center for Behavioral Health and Research Services
Dean James Liszka, College of Arts and Sciences

Appendix I

Example of Breast Cancer Survivorship Care Plan

SAMPLE

Cancer Survivorship Care Plan

This Survivorship Care Plan will facilitate cancer care following active treatment. It may include important contact information, a treatment summary, recommendations for follow up care testing, a directory of support services and resources, and other information [1]

Survivorship Care Plan for Breast Cancer

Prepared by: NearSpace, Inc. on 9/4/2008

General Information

Patient Name	Jane Doe
Patient ID	#121365
Phone	707-555-1211
Date of birth	9/10/1963
Age at diagnosis	45
Support contact	John Doe, 707-555-1212

Care team	
Medical oncologist	Dr. Patricia Ganz, 707-555-1210
General/breast surgeon	Dr. McDermon, 707-555-1213
Radiation therapist	Dr Vascedio, 707-555-1214
Plastic surgeon	Dr. Roman, 707-555-1215
Primary care physician	Dr Vorgis, 707-555-1216
OB-GYN	Dr Drexel, 707-555-1217
Nurse/nurse practitioner	Faith Berght, 707-555-1218
Mental health/social worker	Mary Kratz, 707-555-1219
Other	

SAMPLE

Cancer Survivorship Care Plan

Jane Doe
DOB: 9/10/1963

Background Information

Family history	Multiple relatives
Genetic testing	Ordered, Results:
Major comorbid conditions	Migraine headaches
Echocardiogram or MUGA result	EF = 65%
Additional comments	No notable surgical findings.

Left breast	
Definitive breast surgery	Mastectomy, on 5/6/2008
Lymph nodes	5 removed, 2 positive
Tumor type & stage	Infiltrating ductal, T1, N1
Pathologic stage	Stage II
ER status	Negative
PR status	Negative
HER2 status	Negative

Right breast	
Definitive breast surgery	Mastectomy, on 5/6/2008
Lymph nodes	8 removed, 3 positive
Tumor type & stage	Mixed, T1, N1
Pathologic stage	Stage III
ER status	Negative
PR status	Negative
HER2 status	Negative

SAMPLE

Cancer Survivorship Care Plan

Jane Doe
DOB: 9/10/1963

Treatment Plan & Summary

Patient's height	157.5 cm	
	Pre-treatment	**Post-treatment**
Patient's weight	50.8 kg	54.4 kg
Patient's BSA	1.49 m^2	1.54 m^2
Patient's BMI	20.5	22.0
Date last menstrual period	6/2/2008	
Comments		Dose reduction due to sepsis.

Regimen	**TAC** Docetaxel (Taxotere) 75 mg/m2 iv d1 Doxorubicin (Adriamycin) 50 mg/m2 iv d1 Cyclophosphamide (Cytoxan) 500 mg/m2 iv d1 Q3w x 6 cycles Filgrastim (Neupogen) support	
Chemotherapy agents	# cycles	% dose reduction
Docetaxel	6	25% in cycle 6
Doxorubicin	6	
Cyclophosphamide	6	25% in cycle 6
Filgrastim support		

Anthracycline administered	Doxorubicin, 430 mg (279 mg/m^2)
Treatment on clinical trial	No
Chemotherapy treatment period	6/14/2008 - 10/20/2008
Possible side effects of regimen	Anemia, Fatigue, Hair loss, Infertility, Low blood count, Menopause symptoms, Nausea/vomiting, Neuropathy, Sores in mouth
Reconstruction	Planned: Yes
Radiation therapy	Planned: Yes, completed: 12/20/2008, dose:
Growth factor given	Yes
Grade 3 or higher toxicities	Anemia, Dehydration, Mucositis, Neutropenia, Sepsis, Thrombocytopenia
Hospitalization for toxicities	Yes
Neurotoxicity impairing activities	No
Early termination of treatment	NA-treatment completed

SAMPLE

Cancer Survivorship Care Plan

Jane Doe
DOB: 9/10/1963

Biologic therapy	Planned: No, Prescribed: No

Follow-Up Care

Test	Frequency	Provider to contact
Medical history/physical exam: Yrs 1-3	Every 3 months	Dr. Vorgis
Medical history/physical exam: Yrs 4,5	Every 6 months	
Post-treatment mammography	Every year	
MRI	Every 3 years	
Bone densitometry	Every 3 years	
Pelvic examination	Every year	
Genetic counseling referral	Recommended	Dr. Smithey
Breast self examination	Every month	

Preventive care recommendations	Bone health, Cholesterol monitoring/management, Diet, Exercise, Mental health, Weight management

ASCO Surveillance Guidelines

Medical history and physical (H&P) examination
Visit your doctor every three to six months for the first three years after the first treatment, every six to 12 months for years four and five, and every year thereafter.

Post-treatment mammography
Schedule a mammogram one year after your first mammogram that led to diagnosis, but no earlier than six months after radiation therapy. Obtain a mammogram every six to 12 months thereafter.

Breast self-examination
Perform a breast self-examination every month. This procedure is not a substitute for a mammogram.

Pelvic examination
Continue to visit a gynecologist regularly. If you use tamoxifen, you have a greater risk for developing endometrial cancer (cancer of the lining of the uterus). Women taking tamoxifen should report any vaginal bleeding to their doctor.

SAMPLE

Cancer Survivorship Care Plan

Coordination of care
About a year after diagnosis, you may continue to visit your oncologist or transfer your care to a primary care doctor. Women receiving hormone therapy should talk with their oncologist about how often to schedule follow-up visits for re-evaluation of their treatment.

Genetic counseling referral
Tell your doctor if there is a history of cancer in your family. The following risk factors may indicate that breast cancer could run in the family:

- Ashkenazi Jewish heritage
- Personal or family history of ovarian cancer
- Any first-degree relative (mother, sister, daughter) diagnosed with breast cancer before age 50
- Two or more first-degree or second-degree relatives (grandparent, aunt, uncle) diagnosed with breast cancer
- Personal or family history of breast cancer in both breasts
- History of breast cancer in a male relative

Not Recommended
The following tests are not recommended for routine breast cancer follow-up: breast MRI, FDG-PET scans, complete blood cell counts, automated chemistry studies, chest x-rays, bone scans, liver ultrasound, and tumor markers (CA 15 3, CA 27.29, CEA). Talk with your doctor about reliable testing options.

ASCO® Survivorship Care Plan Surveillance Guidelines ©2008 American Society of Clinical Oncology®

Symptoms to Watch For

Patient should report these signs and symptoms if persistent:

- Abdominal pain
- Arm swelling
- Bone pain
- Chest pain
- Fractures
- Hot flashes or other menopausal symptoms
- New lumps
- Palpitations
- Persistent headaches
- Shortness of breath or difficulty breathing
- Swelling in legs

ASCO® Survivorship Care Plan Surveillance Guidelines. ©2008 American Society of Clinical Oncology®.

SAMPLE

Cancer Survivorship Care Plan

Jane Doe
DOB: 9/10/1963

Potential Late Effects of Cancer Treatment

You may experience the following effects after cancer treatment.

- **Surgery:**
  Numbness, weakness, pain, loss of range of motion (ROM), or arm swelling (lymphedema)
- **Chemo/Biotherapy:**
  Fatigue, ovarian failure with associated menopausal symptoms, neuropathy, cognitive dysfunction, weight gain, psychological distress, and sexual dysfunction; increased risk of leukemia (after anthracycline based therapy), osteoporosis from premature ovarian failure, increased risk of cardiac dysfunction secondary to anthracycline and/or trastuzumab.
- **Radiation:**
  Breast pain, fibrosis, telangectasia, atrophy, poor cosmetic outcome.
- **Hormone therapies:**
  Tamoxifen—hot flashes, increased risk of blood clots, uterine cancer, and stroke.
  Aromatase inhibitors—increased risk of osteoporosis and fracture.

Patricia A. Ganz and Erin E. Hahn, J Clin Oncol 26:759-767.

Resources for Physicians

Late Effects of Cancer Treatment and Survivorship:
Strategies for Primary Care and Oncology Care Providers
A free online Continuing Medical Education (CME) Program available through September 2009, providing 3.0 AMA PRA Category 1 Credits. This educational program has been designed to promote understanding regarding late effects of cancer treatment and survivorship and their role in the long-term surveillance in order to reduce adverse health outcomes of cancer Survivors.

cemedicus.com/cancersurvivorship, click "Launch Activity" link to begin the activity.

Cancer Care for the Whole Patient:
Meeting Psychosocial Health Needs – October 2007
The report by the Institute of Medicine studies the delivery of psychosocial services to cancer patients and their families and identifies ways to improve it.

IOM.edu

Cancer Survivorship Care Planning – November 2005
A report by the Institute of Medicine, based on From Cancer Patient to Cancer Survivor: Lost in Translation, 2006, details the elements of a survivorship care plan as well as frequent questions Survivors may ask.

IOM.edu

From Cancer Patient to Cancer Survivor:
Lost in Transition Report Recommendations – November 2005
The recommendations in this report, taken from the Institute of Medicine's report, From Cancer Patient to Cancer Survivor: Lost in Transition, are directed to cancer patients and their advocates, health care providers and their leadership, health insurers and plans, employers, research sponsors, and the public and their elected representatives.

IOM.edu

American Society of Clinical Oncology® Chemotherapy Treatment and Summary Templates
Developed by volunteer oncologists, these treatment plan and summary templates for breast and colon cancer can be downloaded in a modifiable format allowing oncologists to customize and adapt them to suit their own practices.

ASCO.org

Children's Oncology Group Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent and Young Adult Cancers
These guidelines provide recommendations for screening and management of late effects that may potentially arise as a result of therapeutic exposures used during treatment for pediatric malignancies. They were developed as a resource for clinicians who provide ongoing healthcare to survivors of pediatric malignancies. The screening recommendations in these guidelines are appropriate for asymptomatic survivors of childhood, adolescent, or young adult cancer presenting for routine exposure-based medical follow-up.

survivorshipguidelines.org

Resources for Patients

American Cancer Society (ACS) Guidelines on Nutrition and Physical Activity for Cancer Prevention
Updated every five years, this document is a short version of the ACS Nutrition and Physical Activity Guidelines. It includes how to maintain a healthy weight and how to stay active.

Cancer.org

SAMPLE

Cancer Survivorship Care Plan

CancerCare
CancerCare is a national nonprofit group that gives free support services to those affected by cancer: people with cancer, caregivers, children, loved ones and those who have lost loved ones. These programs include counseling, education, financial and practical help. They are given at no cost by trained social workers. Founded in 1944, CancerCare helps more than 91,000 people each year. And each year, as many as 1.6 million people visit the website to learn more and find resources.

Call 1-800-813-HOPE (4673), send an e-mail to info@cancercare.org, or visit the website at cancercare.org

Cancer.Net™
Cancer.Net™ is the award-winning patient information website of the American Society of Clinical Oncology® (ASCO). ASCO® is the world's leading professional organization representing physicians of all oncology subspecialties who care for people with cancer. This website provides timely, oncologist-approved information to help patients and families make informed health-care decisions. All content is subject to a formal peer-review process by more than 150 medical, surgical, radiation, and pediatric oncologists, oncology nurses, social workers, and patient advocates. In addition, ASCO® editorial staff reviews the content for easy readability. Cancer.Net™ is reviewed on an annual basis or as needed.

Cancer.Net

Employee Assistance Program (EAP)
This service is offered, for the most part, through large employer groups. EAPs help employees and their families deal with issues such as:

- Short and long-term disability
- Personal and emotional concerns
- Legal and financial advice

EAPs can give access without barriers to an open network of community resources and licensed mental health counselors. Employee contact with the EAP is kept private. To learn more, ask your employer about your company's EAP.

Facing Forward: Life After Cancer Treatment
Written by the National Cancer Institute, this booklet shares the feelings and feedback that many people have after cancer treatment. It also offers tips to help people get through this time.

cancer.gov

From Cancer Patient to Cancer Survivor: Lost in Transition - video
This short film by the Institute of Medicine features the stories of cancer survivors and supports the need for a Survivorship Care Plan.

IOM.edu or YouTube.com

SAMPLE

Cancer Survivorship Care Plan

Heal: Living Well After Cancer
Cancer survivors can use the information in this pamphlet for the rest of their lives from the day treatment ends Topics include

- Cancer's after-effects
- Financial security
- Best nutrition and fitness
- Working after cancer
- Faith and belief after cancer
- Insurance strategies

healtoday com

The LIVESTRONG™ Survivorship Center of Excellence
LIVESTRONG™ Survivorship Center of Excellence is funded by the Lance Armstrong Foundation (LAF)

These centers

- Help people living with cancer deal with the emotional, practical and physical issues they face.
- Serve as a one-stop source of information, care and service for cancer survivors, family members and service providers

Centers include·
Abramson Cancer Center, University of Pennsylvania, Philadelphia, PA, 215-615-3371
Dana-Farber Cancer Institute, Boston, MA, 617-632-5100
Fred Hutchinson Cancer Research Center, Seattle, WA, 206-667-2814
Memorial Sloan-Kettering Cancer Center, New York, NY, 212-639-2581
Ohio State University Comprehensive Cancer Center – James Cancer Hospital and Solove Research Institute, Columbus, Ohio, 614-293-6401
UCLA's Jonsson Comprehensive Cancer Center, Los Angeles, CA, 310-206-1404
University of Colorado Cancer Center, Denver, CO, 303-239-3397
University of North Carolina Lineberger Comprehensive Cancer Center, Chapel Hill, NC, 919-966-7230

SAMPLE

Cancer Survivorship Care Plan

National Center for Complementary and Alternative Medicine (NCCAM)
NCCAM is the federal government's lead agency for scientific research on complementary and alternative medicine (CAM) The mission of NCCAM is to:

1. Explore healing practices in the context of science.
2. Train medical researchers.
3 Spread information to the public and professionals.

Call 1-888-644-6226, send an e-mail to info@nccam.nih.gov or visit the website at http //nccam.nih.gov

National Coalition for Cancer Survivorship (NCCS)
NCCS is the oldest survivor-led cancer advocacy organization in the country. Members advocate for quality cancer care for all Americans and empowering cancer survivors. Patient education also is a priority for NCCS, which offers the Cancer Survival Toolbox®. This award-winning audio set is provided to Survivors, caregivers and clinicians at no cost. NCCS believes access to credible and accurate patient data is vital to asking for and getting quality cancer care.

Call 1-888-650-9127 or visit the website at canceradvocacy org.

Northern California Cancer Center (NCCC)
The NCCC is a nonprofit group that works with researchers, patients, educators, community based groups and academic centers. The NCCC is committed to preventing cancer and improving the quality of life for those living with cancer

The NCCC studies:

- The causes of cancer
- Cancer survivorship
- Cancer screening

The NCCC manages:

- A statewide breast and cervical cancer referral service for low-income women
- A statewide NCI-Cancer Information Service Partnership Program that focuses on improving outcomes that have to do with cancer. (This is done mainly in places where people may not be getting the medical care they need).
- A community education program for patients and families, the general public and health care providers.

Call 1-510-608-5000 or visit the website at nccc org

SAMPLE

Cancer Survivorship Care Plan

The Wellness Community
This is a global nonprofit group that gives support, education and hope to people with cancer and their loved ones. They can learn vital skills that let them regain control, reduce isolation and restore hope by taking part in professional-led support groups, workshops, nutrition and exercise programs, as well as stress reduction classes. All programs are free.

Call 1-888-793-WELL send an e-mail to help@thewellnesscommunity.org or visit the website at thewellnesscommunity.org.

Endnotes

Note 1: Important caution. This is a summary document whose purpose is to review the highlights of the cancer chemotherapy treatment plan for this patient. This does not replace information available in the medical record, a complete medical history provided by the patient, examination and diagnostic information, or educational materials that describe strategies for coping with cancer and adjuvant chemotherapy in detail. Both medical science and an individual's health care needs change, and therefore this document is current only as of the date of preparation. This summary document does not prescribe or recommend any particular medical treatment or care for breast cancer or any other disease and does not substitute for the independent medical judgment of the treating professional.